A FAMILY CENTERED, POSITIVE BEHAVIOUR SUPPORT APPROACH TO SLEEP PROBLEMS IN A CHILD WITH AUTISM

by

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Abstract

Parents of children with autism spectrum disorders (ASD) report a significantly higher frequency and severity of sleeping problems than typically developing children and children with other disabilities. Sleeping problems most commonly reported include difficulties with sleep onset, maintenance, irregular sleep routines, and co-sleeping. A number of studies have used behavioural interventions to treat such sleeping problems. However, a number of methodological limitations have been identified with such studies. Additionally, there are a number of other clinical limitations that may affect the acceptability, meaningfulness, and sustainability of treatment outcomes. A Positive Behaviour Support (PBS) approach to behavioural interventions has been identified in the research as a viable approach to address such outcomes. This study evaluated an approach to behavioural intervention that synthesized evidence-based practices in PBS and the treatment of sleep problems in children with ASD. This study investigated the effectiveness of a parent-implemented PBS plan to improve the sleep problems of a child with ASD during a bedtime routine. A 4-year-old child with a diagnosis of ASD and his mother participated in the study. The study employed a single-subject case study design, using a multiple probe strategy. Results indicated improvements in child sleep behaviour and participation during the bedtime routine following implementation of the PBS intervention. The results are discussed with reference to previous research, unique contributions to the literature, future directions, and implications for practitioners and researchers who are involved in interventions for children with ASD and sleep problems.
Preface

Ethics approval was given by the Behavioural Ethics Research Board (BREB) on July 28, 2009 and renewed the following year. The certificate number is H09-00956.
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# Chapter: Introduction

## 1.1 Sleep Problems in Children with Autism

*Autism* is often used to describe a spectrum of neurobehavioural developmental disabilities characterized by three core features, including: (a) qualitative impairments in social interaction; (b) qualitative impairments in communication; and (c) a restricted range of activities and interests (American Psychiatric Association, 1994). In addition to these core features, there are a number of secondary behavioural problems that also exist in children with ASD, and among these is the presence of sleep problems (Hering, Epstein, Elroy, Iancu & Zelnick, 1999; Johnson, 1996; Norton & Drew, 1994; Rapin, 1991). For example, The Treatment and Education of Autistic and Communicatively Handicapped Children (TEACCH) program lists sleep problems as a major behavioral management issue (Van Bourgondien, 1993). A “sleep problem” as it relates to a child is commonly described as a sleep behaviour that is disturbing in some way to the child, the child’s family, or both; and is distinct from a sleep disorder which implies an underlying abnormal physical function (Ferber, 1996).

Research indicates that a significant number of individuals with developmental disabilities have sleep problems, with prevalence among such individuals estimated as high as 88%, as determined by actigraphy (i.e., data collected from a sensor worn by the child at night to measure gross motor activity) or parent report (Didden & Sigafoos, 2001; Piazza et al., 1996; Richdale, 1999; Richdale & Prior, 1995; Wiggs & Stores, 2004). Within this range, children with autism in particular have the highest prevalence rates (Patzold et al., 1998; Wiggs & Stores, 1996) and sleep problems in children with autism are reported to be more frequent and more severe than those of typically developing children (Schreck & Mulick, 2000). For example, approximately only 30% of typically
developing infants and preschool children have sleep problems (Owens, 2000) with the percentage decreasing in school-aged children (Stein, 2001). Although Richdale and Prior (1995) found that there was some improvement in sleep problems with increasing age in children with autism, older children were still likely to suffer from sleep problems.

Studies on the sleep of children with autism identify the types of sleep problems most commonly reported by parents of children with autism to include: difficulties with sleep onset (bed refusal and/or difficulty settling), sleep maintenance (frequent and lengthy episodes of night waking and/or early morning waking) and irregular sleep routines (Patzold et al., 1998; Richdale, 1999; Richdale & Prior, 1995; Schreck & Mulick, 2000; Stores et al., 1998). Research indicates that parents of children with autism often resort to co-sleeping (i.e., sleeping in the same bed as the parent) in order to deal with such sleep problems (Weiskop, Matthews & Richdale, 1999; Wolf et al., 1964), which can also become a problem in and of itself. Additionally, such children often exhibit multiple sleep problems (Clements et al., 1986; Piazza & Fisher, 1991; Piazza et al., 1996).

Apart from the aforementioned sleep problems, other sleep problems reported by parents include enuresis (i.e., bedwetting), obstructive sleep apnea syndrome (i.e., sleep disordered breathing), bruxism (i.e., teeth grinding), nightmares and/or night terrors, and excessive daytime sleepiness (Richdale, 1999; Schreck & Mulick, 2000; Stores, Stores, & Buckley, 1996).

The increased frequency and severity at which children with autism experience sleep problems is of particular concern as it affects not only the child but the family as a whole. The presence of sleep problems in children with developmental disabilities,
including children with autism has been associated with daytime problem behaviours such as daytime fatigue, an increase in incidence and severity of problematic daytime behaviours (namely, hyperactivity, aggression, self-injurious behaviour and tantrums), attachment to routines, poor concentration, decreased cognitive functioning, and lower quality interactions with caregivers (Hoffman et al., 2005; O’Reilly & Lancioni, 2000; Patzold et al., 1998; Richdale et al., 2000; Schreck, 2001; Symons, Davis & Thompson, 2000; Wiggs & Stores, 1996). Consistent with research associating sleep problems with daytime problem behaviours, Durand et al. (1996) found fewer daytime problem behaviours following successful treatment of sleep problems in two children with developmental disabilities.

Additionally, sleep problems in children with autism have been associated with a number of adverse side effects on parents including an increase in daytime fatigue, stress and daytime irritability and decreased participation in social activities (Doo & Wing, 2006; Quine, 1991; Schreck & Mulick, 2000).

These findings demonstrate the varied and complex nature of sleep problems in children with autism. The severity and frequency, combined with associated parental stress and daytime behavioural problems suggest a tremendous need by families for effective intervention (Patzold et al., 1998; Richdale, 1999; Weiskop et al., 2001).

1.2 Behavioural Interventions for Sleep Problems in Children with Autism

Although many types of interventions are used to treat sleep problems, research indicates that behavioural interventions are preferable for parents of children with autism (Wiggs & Stores, 1996). Behavioural interventions for sleep problems do not involve changing the child’s sleep per se, but rather changing the parent’s behaviour towards the child at bedtime and during the sleep period, which in turn alters the child’s behaviour.
Such interventions are designed to promote good sleep behaviour and correct problem sleep behaviour and they are generally the same behavioural interventions used with children without autism (Wiggs & France, 2000). Successful behavioural interventions for sleep problems may reduce the severity of problematic daytime behaviours and improve a child’s responsiveness to other interventions (Hoffman et al., 2005; Schreck, 2001). Additionally, successful interventions are likely to reduce parental stress related to sleep problems in children with autism (Wiggs & Stores, 1996).

There is a growing body of research documenting the efficacy of behavioural interventions to treat sleep problems in typically developing children (Weiskop et al., 2001). However, there is a shortage of such research for children with developmental disabilities, specifically autism. Despite the prevalence of sleep problems in children with autism, there is a dearth of controlled intervention research and long-term follow-up on the efficacy, effectiveness, and acceptability of sleep interventions for such children (Schreck, 2001; Weiskop, Richdale & Matthews, 2005).

This section will review the literature on behavioural interventions for sleep problems in children with autism, namely: (a) bedtime routines; (b) bedtime scheduling; (c) sleep restriction; (d) non-graduated extinction; (e) graduated extinction; (f) graduated withdrawal; and (g) faded bedtime with response cost (FBRC).

1.2.1 Bedtime Routines

A bedtime routine is a regular and well-structured series of pre-bedtime events which typically involves the following steps: having a snack, taking a bath, brushing teeth, putting on pajamas, reading a story, turning the lights off, and going to sleep (Schreck, 2001). The rationale behind this type of intervention is that continuous use of a
bedtime routine will serve as a stimulus for sleep. Although no studies exist that focus solely on the use of bedtime routines as a behavioural intervention for sleep problems, they are often used as a component of behavioural interventions (see Christodulu & Durand, 2004; Durand et al., 1996; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964).

1.2.2 Sleep Scheduling

Sleep scheduling involves implementing consistent and age-appropriate bed times and wake-up times (Wiggs & France, 2000). Sleep scheduling is a relatively straightforward intervention for parents to implement (Mindell et al., 1996; Wiggs & Stores, 1996), although some parents may be reluctant to change their child’s bedtime to an age-appropriate time, as it may interfere with their free time at night (Durand et al., 1996). For example, in one study by Durand et al. (1996) one set of parents did not agree with the age-appropriate bedtime of 10pm for their 12-year old boy with autism. Therefore, he was allowed to play quietly in his bedroom from 8pm to 10pm before an alarm clock sounded and one of his parents put him to bed. At the end of treatment, the boy’s sleep had improved, however he still took an average of approximately 44 minutes to fall asleep. In such cases, putting the child in bed at a regular time and allowing the child to remain awake does not help to establish the association between going to bed and sleeping (Piazza et al., 1997). Rather, going to bed may serve as cue for a number of other behaviors preceding sleep, whether it is tantrums or quiet play activities (Piazza et al., 1997).

Similar to bedtime routines, there is no research that focuses solely on the use of bedtime scheduling for sleep problems in children with autism, and it is often used as a
component of behavioural interventions such as for Durand et al. (1996). However, Piazza et al. (1997) compared bedtime scheduling to FBRC, as outlined below.

1.2.3 Sleep Restriction

Sleep restriction involves restricting the amount of time in bed to only time when the child is sleeping (Christodulu & Durand, 2004). Initially, sleep is restricted to 90% of the average number of hours of actual sleep time the child typically receives each night. In order achieve this, the child’s bedtime is set to a later time and/or the child is awakened earlier in the morning. During the sleep restriction intervention, if the child remains awake in bed and/or exhibits problem behaviours, he or she is removed from bed and allowed to engage in a relaxing activity until he or she appears tired. However, if the child falls asleep and does not exhibit problem behaviours for a pre-determined number of nights, the amount of time asleep is then increased by 15 minutes until the desired sleep schedule is achieved. The main strength of sleep restriction is that it is relatively easy for parents to implement on a regular basis and does not result in disruptions at bedtime or during night waking, as in other interventions such as non-graduated and graduated extinction (Christodulu & Durand, 2004; Durand & Christodulu, 2004).

However, researchers have noted that parents may be initially reluctant to implement a sleep restriction intervention if they believe that their child’s behaviour during night wakings may deteriorate as a result of restricted or limited sleep (Durand & Christodulu, 2004).

Using a single-subject multiple baseline design, Durand and Christodulu (2004) investigated the effectiveness of a sleep restriction intervention to reduce the settling and night waking problems of two 4- year-old girls with developmental disabilities, including one girl with autism. Both girls displayed bedtime disturbances and frequent night
waking with severe tantrums lasting between 2-4 hours. Additionally, the parents of both children used co-sleeping as a method of dealing with their child’s sleep problems. Introduction of the sleep-restriction intervention resulted in the rapid elimination of bedtime disturbances and co-sleeping, and a reduction in the frequency and duration of night wakings for both children. Although night waking was not completely eliminated for either of the children, the children no longer exhibited tantrums during such wakings and therefore were not perceived as disruptive. The child’s parents perceived the intervention to be socially valid (i.e., acceptable and important). However, no follow-up data were collected, and therefore the long-term effects of the intervention could not be assessed. Despite these successes, the authors also noted an increase in other sleep problems in one of the participants, such as sleepwalking and night terrors upon implementation of the sleep-restriction intervention. Durand and Christodulu (2004) hypothesized that the introduction of the sleep-restriction intervention produced an alteration in sleep stages, specifically a disruption of Stages 3 and 4 of non-rapid eye movement (NREM), which have previously been associated with sleepwalking and night terrors. However, such disruption was temporary and sleepwalking and night terrors disappeared once the child’s length of sleep had increased.

In a similar study, Christodulu and Durand (2004) used a single-subject multiple-baseline design to investigate the effectiveness of sleep restriction to reduce the bedtime disturbances and night waking in four children (ages 2-5) with developmental disabilities, including two children with autism. Following the implementation of bedtime routines, sleep restriction was added to the intervention plans. Unfortunately, shortly following the beginning of the study, one of the children became ill and was not able to participate in
the intervention. Notwithstanding, sleep restriction was effective in eliminating bedtime disturbances and significantly reduced the average number of night wakings per week in the remaining three children. Additionally, the duration of such bedtime disturbances and night wakings were significantly reduced in these children. Although the average amount of sleep per night was below that which would be considered developmentally appropriate for the children’s ages at the end of the intervention, the quality of the children’s sleep had significantly improved and the researchers reported that the children did not appear to experience any adverse side effects as a result. Data collected during a 1 month follow-up indicated that treatment gains were maintained for all children. Similar to the previous sleep restriction study, the intervention had high social validity with parents expressing satisfaction with their child’s behaviour at bedtime and noting that it was easier to put their child to bed at night.

1.2.4 Non-graduated Extinction

Among the studies utilizing behavioural interventions to address sleep problems in children with autism, non-graduated extinction has been used most frequently. Non-graduated extinction involves withholding reinforcement for undesirable sleep behaviour. Typically the child is placed in his or her bed, the parent leaves the room and does not return until morning unless the child is sick or in physical danger (France, Henderson & Hudson, 1996). Non-graduated extinction may be considered suitable in those situations in which a functional assessment indicates that sleep problems are connected with contingencies of positive reinforcement, such as parental attention. Notwithstanding, researchers also report that parents may be reluctant to use this type of behavioural intervention. Non-graduated extinction often causes an extinction burst which can be stressful to parents. This procedure also may not be suitable for children with self-
injurious behaviour or if illness is suspected due to concerns over the child’s personal safety (Durand, 1998; France, Blampied & Wilkinson, 1991). Several studies have examined the use of non-graduated extinction to address the sleep problems in children with autism.

In a case study by Wolf et al. (1964), a non-graduated extinction and mild punishment procedure was combined with a bedtime routine to deal with the bedtime tantrums of a 3.5-year-old boy with autism. After completing his bedtime routine, the boy was placed in his bed with the door open. If the boy left his bed and/or had a tantrum, the door was closed briefly (punishment) and the boy was given no attention (extinction). Once he returned to bed and/or the tantrum subsided, the door was re-opened. In the initial 5 days of the intervention, the researchers noted an extinction burst (i.e., an increase in the frequency and type of unwanted behaviour); however, by the sixth night, the tantrums were almost completely eliminated. Additionally, no sleep problems were evident at a 6 month follow-up. The intervention was initially conducted by staff in a hospital; however the researchers reported that the positive results successfully transferred to the boy’s home environment.

In a non-concurrent multiple baseline design across participants, Didden et al. (2002) focused on the use of extinction procedures (combined with anticonvulsant medication for one child) to treat the sleep onset, sleep maintenance (night waking) and co-sleeping problems of three children with developmental disabilities (ages 1-7), including one 6-year-old boy with autism. Disruptive behaviours exhibited by the children at bedtime and during night wakings included calling out, crying and self-injurious behaviours, such as head banging. In all of the children, extinction was effective
in reducing bedtime problem behaviours and night waking, and results were maintained
during a 6 month follow-up. However, the frequency of nighttime disruptive behaviours
showed variability during treatment, with temporary increases due to environmental and
social changes as well as physical illness. Additionally, the authors noted in their
limitations that parents found the non-graduated extinction procedure difficult to
implement and that they were afraid that the procedure may cause psychological trauma
to their child or that the child may feel afraid or rejected. Parents were also concerned
that the child’s lengthy episodes of crying at night might disturb the neighbors.

In a case study, Weiskop et al. (2001) used non-graduated extinction for the sleep
maintenance (in particular, night waking) and co-sleeping problems of a 5-year-old boy
with autism. During baseline, every night the boy was settled to sleep with his bottle on
his mother’s lap in the living room and once asleep he was brought to his parents’ room,
where he slept the remainder of the night. Additionally, baseline measures indicated that
the boy had an average of 3-5 night wakings per week. Parents were taught how to use a
sleep diary and were given information and training on behavioural techniques including:
(a) analysis of antecedent-behaviour-consequences; (b) implementation of bedtime
routines; (c) use of reinforcement; and (d) non-graduated extinction. After the second
week of intervention, the researchers reported improvements in settling, a decrease in
night waking, and complete elimination of co-sleeping. However, the data showed
evidence of an extinction burst at week 6 of the intervention, with 43 pre-sleep
disturbances, a number that well exceeded baseline levels. Improvements in self-settling,
co-sleeping, and night waking were maintained at 3 and 12 month follow-ups. Although
the researchers reported no pre-sleep disturbances at 3 months, they reported an average
of once per week at 12 months, however such disturbances were only to use the toilet. Additionally, the parents’ goals were achieved and parent satisfaction was reported as high.

Weiskop and colleagues later conducted a second study using similar procedures as above. Five of the 13 children treated in this study had diagnoses of autism (Weiskop et al., 2005). Similar to the first study, parents were taught to use a sleep diary and were given information and training on the same behavioural techniques. Results indicated improvements in sleep onset, sleep maintenance and co-sleeping problems in all of the children, including those with autism. Additionally, the parents noted the intervention as high in social validity and improvements were maintained at 3 month and 12 month follow-ups.

1.2.5 Graduated Extinction

Since non-graduated extinction is sometimes perceived as stressful to parents, a modification of this intervention, “graduated extinction” has been developed. Graduated extinction, first described by Ferber (1985) involves removing reinforcement for undesirable sleep behaviour for a set period of time. Using this intervention, parents ignore bedtime tantrums or night waking for a specified period of time (typically 5 minutes) before re-entering the bedroom and briefly calming the child with as little attention as possible before exiting. In a variation of this intervention, the specified interval for ignoring the child's problem behaviour progressively increases over time, usually over successive nights. Weaknesses of this type of intervention include the possibility that the child’s problem behaviour could be shaped into progressively longer durations, and that parents may increase the length and/or value of reinforcement during the checking procedure (France, 1996).
Durand et al. (1996) used a multiple baseline design to evaluate the treatment efficacy of a graduated extinction procedure to treat the sleep onset and night waking problems of a 12-year-old boy with autism and a 2-year-old girl with autism. Before treatment, both children had severe tantrums that occurred nightly ranging from 15 minutes to 4 hours, and the parents of both children used co-sleeping to eliminate the unwanted behaviours. During intervention, parents left the room at a pre-determined bedtime, and returned to encourage their child to sleep at intervals ranging from 2 to 5 minutes. These intervals were extended across subsequent nights. Following treatment, there was a significant decrease in tantrums for both children with autism; however, neither child’s problem behaviours were completely eliminated. The authors noted that the flexibility within this type of intervention allowed for individual differences in parent’s tolerance of tantrums, as what may seem like a short interval for one parent may seem much longer for another (Durand et al., 1996). Additionally, the parents reported that the ability to check on their child between tantrums made the procedure easier to tolerate compared to non-graduated extinction. As noted by Durand et al. (1996), this aspect may result in higher rates of parent compliance to treatment.

1.2.6 Graduated Withdrawal

Graduated withdrawal (also known as stimulus fading) involves gradually moving a caregiver progressively farther away from a child’s bed until full separation is achieved (Howlin, 1984). Graduated withdrawal may be most appropriate when settling is the main sleep problem (Allison et al., 1993; Howlin, 1984) and the onset of sleep is under inappropriate stimulus control (i.e., parental presence). Thus, the gradual fading of parental presence serves as a gradual stimulus manipulation to promote independent sleep onset (Howlin, 1984; Lancioni & Smeets, 1986). Unlike non-graduated extinction, an
advantage to this type of intervention is that results can be accomplished relatively rapidly and with decreased levels of stress for the child and/or the family (Howlin, 1984).

In a case study, Howlin (1984) applied graduated withdrawal to the sleep onset, night waking and co-sleeping problems of a 5.5-year-old boy with autism and epilepsy. Prior to implementing the intervention, the boy was not able to fall asleep without his mother’s presence. Using an inflatable mattress, the boy’s mother progressively moved from beside the boy’s bed, to the hallway, and finally to her own room. Full separation was achieved over a 2 month period, and was maintained at a 6 month follow-up. Night waking also decreased during this period; however, it still occurred 2-3 times per week. Despite the success of the aforementioned study, some researchers have encountered some limitations in using graduated withdrawal, namely that some parents may be reluctant to alter their sleeping arrangements. Also, depending on the situation, parents may experience increased stress while attempting to tolerate their child’s tantrums during the initial stages of the withdrawal of their presence (France, 1996).

1.2.7 Faded Bedtime with Response Cost (FBRC)

In faded bedtime, average baselines are calculated to find a bedtime that most typically results in the child falling asleep within 15 minutes of being put to bed (Piazza et al., 1997). The child’s bedtime is then delayed by 30 minutes. If the child falls asleep within 15 minutes for two nights, the bedtime is moved 30 minutes earlier the subsequent night. If the child does not fall asleep within 15 minutes, the bedtime is moved 15 minutes later the subsequent night. This procedure is applied to successive nights until the child's sleep onset is "faded" toward a predetermined bedtime goal. If rapid sleep onset is not observed within the 15 minute time period, a response cost procedure can be added in which the child is removed from bed and kept awake for 30 to 60 minutes
(Piazza et al., 1997). This process is repeated until the child falls asleep within 15 minutes. On the subsequent night, the faded bedtime procedure is begun.

In a randomized trial, Piazza et al. (1997) compared two behavioural interventions: FBRC and bedtime scheduling (with scheduled waking and no daytime sleep) for the sleep onset and maintenance (both night and early morning waking) problems of 14 children, including 5 children with autism. One group of seven children, including three with autism was treated with FBRC. The second group of seven children, including two children with autism, was treated with bedtime scheduling. The results of the study indicated that the sleep problems of the children in the FBRC group improved significantly as compared to the group receiving only bedtime scheduling. Of the three children receiving the FBRC intervention, two of the children’s sleep problems were almost completely eliminated. Conversely, improvements were generally small to minimal for all of the children receiving the bedtime scheduling intervention. The results suggest that FBRC may be a successful intervention for sleep problems compared to bedtime scheduling. However, no follow-up data were gathered and so the durability of the FBRC intervention could not be assessed.

Although FBRC appears to be successful, some difficulties have been reported, namely the time commitment required to implement the intervention (Piazza et al., 1997). Additionally, some parents may be reluctant to initially changing their child’s bedtime to a later time and/or to stay awake with their child (Piazza et al., 1997).

1.3 Clinical Strengths

Collectively, these studies offer empirical evidence of the effectiveness of behavioural interventions to improve sleeping problems in children with autism. Additionally, each of these studies contain one or more features of a successful approach
to such interventions that results in effective, meaningful and sustainable outcomes for both the child and the family. These features include the use of: (a) assessment and intervention procedures in typical home settings with family members as interventionists (e.g., Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Howlin, 1984); (b) initial parent training and therapist support (e.g., Durand et al., 1996; Howlin, 1984; Weiskop et al., 2001; Weiskop et al., 2005); (c) functional assessment procedures to guide intervention planning (e.g., Christodulu & Durand, 2004; Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964); and (d) multicomponent interventions (that include antecedent and consequence procedures) (e.g., Christodulu & Durand, 2004; Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Piazza et al., 1997; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964), each of which is described below.

1.3.1 Assessment and Intervention Procedures in Typical Home Settings with Family Members as Interventionists

Of the studies reviewed, the majority of the studies assessed and implemented interventions in the child’s natural sleep environment with parents as interventionists (e.g., Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Howlin, 1984). Parents were trained by the researchers to implement the intervention strategies independently with their child. An advantage of using this type of approach is that it represents a form of empowerment for the families involved in the study, and is likely to contribute to the sustainability of the intervention (Moes & Frea, 2002). Additionally, by addressing problem behaviour in typical home settings (e.g., a bedtime routine), interventionists support the natural efforts of families to construct routines that are acceptable, meaningful, and sustainable (Bernheimer & Keough, 1995). Only in Wolf et
al. (1964) and Piazza et al. (1997) did parents play a minimal role. In these studies, the interventions were conducted outside of the family home and implemented by staff in a hospital or a treatment centre.

1.3.2 Initial Parent Training and Therapist Support

In the initial phase of a parent-implemented intervention, the main goal is to provide families with the training and implementation support necessary to ensure success in implementing the intervention and improving problem behaviours (Lucyshyn et al., 1997). In the studies reviewed, such support was most commonly provided in the form of initial parent training through direct teaching and modeling of intervention strategies by a therapist (e.g., Durand et al., 1996; Howlin, 1984; Weiskop et al., 2001; Weiskop et al., 2005). In some cases, parent training was supplemented with written information and parent checklists (e.g., Weiskop et al., 2001; Weiskop et al., 2005). Additionally, a therapist often provided ongoing telephone consultation throughout the training and intervention process in order to check progress, answer parent’s questions, collect data and praise parents’ success (e.g., Durand et al., 1996; Howlin, 1984; Weiskop et al., 2001; Weiskop et al., 2005).

Although therapist support is often cited as being costly and time consuming, it allows for monitoring and reinforcing a family's progress, detecting any inappropriate use of principles or misunderstandings of concepts and helping parents to generalize intervention strategies to other problem behaviours and new family settings (Webster-Stratton, 1990). For example, Weiskop et al. (2005) noted in their limitations section that, although the therapist support was quite time consuming, the intervention would have not been as successful without it since the family had other significant stressors and therefore benefited from the regular reinforcement and guidance provided by the therapist. It
should be noted, however, that although some families may benefit from therapist support such as Weiskop et al. (2005), other families may not need this level of implementation support in order to carry out the intervention with fidelity (Singer, Goldberg-Hamblin, Peckham-Hardin, Barry & Santarelli, 2002).

1.3.3  Functional Assessment Procedures to Guide Intervention Planning

A functional assessment involves collecting information through interviews and observations to understand the underlying function or purpose of problem behaviour. The main objective of conducting a functional assessment is to gather information that will improve the effectiveness of a behavioural intervention (Horner, Albin, Sprague & Todd, 1999). All of the studies reviewed, except Howlin (1984) and Piazza et al. (1997), conducted some form of pre-treatment functional assessment in order to identify the controlling variables of individual sleep problems. This is important as a functional assessment contributes to the overall success of an intervention. For example, in a meta-analysis of intervention effectiveness for problem behaviours (including sleep problems) in individuals with intellectual disabilities, Didden et al. (1997) found that treatments based on the results of a functional assessment had higher effect sizes than those that were not based on an functional assessment.

1.3.4  Multicomponent Interventions

Interventions that consist of multiple components (known as “multicomponent interventions”) include, at the very minimum, the use of both antecedent and consequence strategies, and in some cases teaching strategies. Antecedent strategies involve introducing stimuli that occasion positive and/or removing stimuli that trigger problem behaviour. The stimuli to be introduced or removed can include, among other things, features of the environment, types of social interactions, or particular activities
Consequence strategies involve: (a) the removal of reinforcing events, items, or interactions that may follow problem behaviors; and (b) the use of positive reinforcement to increase or maintain the occurrence of particular appropriate behaviors (Duda et al., 2004). All of the studies reviewed, except Howlin (1984) used multicomponent interventions that included both antecedent and consequence strategies. In addition to antecedent and consequence strategies, a few studies utilized teaching strategies (e.g., Weiskop et al., 2001; Weiskop et al., 2005). For example, in Weiskop et al. (2001) parents taught their child the bedtime routine by using visuals and by modeling the components of the routine using a doll.

Research on problem behaviour suggests that multicomponent interventions are associated with better treatment outcomes. In a recent meta-analysis, Didden, Duker, and Korzelius (1997) examined 482 treatment studies and found that behavioral interventions that included, among other things, multiple intervention components were associated with larger effect sizes.

1.4 Clinical Limitations

The studies reviewed also evidenced a number of limitations including: (a) limited collaboration with parents during assessment and treatment planning; (b) insufficient attention to the contextual fit of the intervention; (c) minimal implementation support during transitional and sustaining phases; and (d) ad-hoc identification of potential obstacles to generalization and maintenance.

1.4.1 Limited Collaboration with Parents during Assessment and Treatment Planning

Even though the majority of the studies assessed and implemented interventions in typical home settings with family members as interventionists, these studies do not
appear to reflect the recent emphasis on the development of “parent-professional collaborative partnerships” in the context of behavioural interventions in the home. Lucyshyn and colleagues (2002) describe a collaborative partnership with families as,

…the establishment of a truly respectful, trusting, caring and reciprocal relationship in which interventionists and family members believe in each other’s ability to make important contributions to the support process; share their knowledge and expertise; and mutually influence the selection of goals, the design of behaviour support plans, and the quality of family-practitioner interactions (Lucyshyn et al., 2002, p.12).

Families have been identified as being an integral part of the assessment, planning and intervention process because they are the single most knowledgeable source of information on their child’s strengths, needs, preferences, and learning histories (Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002; Stroul & Friedman, 1996). As such, family member involvement would include, for example, active participation in functional assessment activities, in the selection of treatment goals and intervention activities, in the negotiation of implementation support, and in the review of data.

Of all the studies reviewed, parent-professional collaborative partnerships were only evident in Weiskop et al. (2001) and Weiskop et al. (2005) where parents collaborated with the researchers throughout the assessment, planning and intervention process. Parents took part in semi-structured interviews, and recorded sleep behaviour in diaries, both of which formed the basis of the functional analysis. The parents determined the components of a bedtime routine for their child, and were offered a choice of type of extinction procedure (non-graduated extinction, graduated extinction or ignoring with parental presence) to be used during intervention. In addition, Weiskop et al. (2001) and Weiskop et al. (2005) used the Goal Achievement Scale (GAS) to negotiate parent goals.
and to include the parents’ perspective in regard to the clinical significance of change in sleep behaviour and program success.

It is well recognized in the behavioural parent training literature that parent-professional collaborative partnerships such as Weiskop et al. (2001) and Weiskop et al. (2005) are more likely to result in effective, meaningful and sustainable intervention outcomes for both the families and children involved (see Buscbacher, Fox & Clarke, 2004; Friesen & Stephens, 1998; Forehand & Gotchick, 2002; Lucyshyn, Albin, Horner, Mann, Mann & Wadsworth, 2007; Lucyshyn, Dunlap, & Albin, 2002; Moes & Frea, 1999; Vaughn, Dunlap, Fox, Clarke & Bucy, 1997; Webster-Stratton & Herbert, 1993). As noted by Forehand and Gotchick (2002), “the quality of the relationship between parents and the therapist has been identified as a critical factor in parental compliance or resistance [to the intervention]...accounting for up to 45% of the variance in predicting treatment outcomes” (p. 382). Also, Brookman-Frazee and Koegel (2004) used a repeated reversal design to compare a parent as interventionist approach with a collaborative partnership approach to a behavioural intervention targeting communications skills for three children with autism. The results indicated that forming a parent-professional collaborative partnership positively affected both parent and child intervention outcomes. When compared to the parent as interventionist approach, parents participating in the collaborative partnership approach showed lower levels of stress and higher levels of confidence. Children demonstrated more positive affect (i.e. happiness and interest), higher levels of responding, and higher levels of engagement.

1.4.2 Insufficient Attention to the Contextual Fit of the Intervention

As mentioned above, the majority of the studies conducted a functional assessment prior to implementing the sleep intervention. In addition to identifying the
function of problem behaviour, a functional assessment also will shed light on: (a) setting events that set the stage for problem behaviour; (b) antecedent stimuli that trigger problem behaviour; and (c) consequences that maintain problem behaviour (Horner et al., 2000). Functional assessments also helpful in identifying child variables such as the child’s strengths, abilities and preferences (Albin et al., 1996; Lucyshyn et al., 2002).

However, a functional assessment does not directly address family variables such as the goals, values, cultural beliefs, resources, social supports, sources of stress, and skills of family members (Albin et al., 1996; Lucyshyn et al., 2002; Moes & Frea, 2002). Also, a functional assessment does not address environmental variables not directly related to the child’s problem behaviour that may promote or hinder the parents’ ability to implement behavioural interventions in the daily routines of family life (Albin et al., 1996). Such environmental variables may include the families’ living arrangements, the way in which family routines are organized, the presence of extended family members or siblings, the number of family members participating in the routine and the resources available to the family during the routine. Shared bedrooms, for example, may interfere with an intervention based on ignoring a child’s problem behaviour. Other family or environmental variables that may affect a parents’ ability to implement behavioural interventions include parental illness, major life transitions, employment problem or marital distress (Lucyshyn et al., 2002). This is an issue as family members play an integral part in implementing the intervention. Therefore, addressing such family or environmental variables when developing a behavioural intervention for sleep problems may provide essential if the goal is to achieve meaning and sustainable behaviour change.
To address these variables, Albin et al. (1996) and Lucyshyn et al. (2002) have argued that behavioural interventions, in addition to being technically sound, also need to be “contextually appropriate” or possess a good “contextual fit.” Contextual fit represents interventions that are compatible with variables related to: (a) the child for whom the plan is designed; (b) the family members implementing the plan; and (c) the environment in which the plan will be implemented (Albin et al., 1996; Lucyshyn et al., 2002). When an intervention has good contextual fit, families are more likely to view the intervention as acceptable and feasible, implement the intervention strategies accurately, apply the intervention strategies to other problem behaviours and new family settings, and continue to use the intervention strategies for sustained periods of time (Albin et al., 1996; Lucyshyn et al., 2007; Moes & Frea, 2002).

To achieve a contextually appropriate behavioural intervention with families, Albin et al. (1996) recommend the supplemental use of a “goodness-of-fit assessment” along with a functional assessment, to determine the family and environmental variables that may support or impede the successful implementation of the intervention. For example, if a goodness-of-fit assessment reveals that a family is experiencing one or more stressors such as parental illness, major life transitions, employment problems or marital distress, it is important to ensure that family-centered supports are in place for families so that the family experiences the stability necessary to implement the intervention (Lucyshyn, Kayser, Irvin & Blumberg, 2002).

Initial research supports the identification of family variables to improve the contextual fit of behavioural interventions for children with disabilities. For example, Moes and Frea (2002) investigated the occurrence of problem behaviour in children with
autism and how individual family variables can be used to individualize or “contextualize” Functional Communication Training (FCT) within family routines. The researchers used a multiple baseline design across participants that included four phases: (1) baseline, (2) standard FCT intervention, (3) contextualized FCT intervention, and (4) follow-up. The researchers addressed family variables unique to families of children with autism including: (a) increased caregiving demands, (b) limited access to social support networks, and (c) restrictive patterns of social interactions. The researchers found that the contextualized FCT intervention did not interfere with the traditional FCT methods and that by incorporating individual family variables and contextualizing the FCT intervention packages, the overall effectiveness of the behavioral interventions was not compromised. In addition, by modifying the intervention package to include unique family variables, the families’ perceptions of FCT intervention improved and may have contributed to the sustainability of the reductions in problem behaviour during follow-up.

Of particular note, culturally-based values, beliefs and parenting practices have not yet been addressed in research on sleep problems in children with autism. Many sleep practices are unique to the cultures in which they are embedded, and therefore families from different cultures may define a ‘sleep problem’ differently (Owens, 2004). Owens (2004) identifies a number of sleep practices that are influenced by cultural practices and beliefs including: co-sleeping, bedtime routines, sleeping arrangements, napping and parental expectations regarding ‘normal’ amounts of sleep in children. A goodness-of-fit assessment will reveal relevant variables related to the family’s culture and help to create an intervention that is compatible with culturally-based values, beliefs and parenting
practices. Given the increased prevalence of cultural diversity in North American society, this area of research is expected to garner more attention in future.

1.4.3 **Minimal Implementation Support during Transitional and Sustaining Phases**

In addition to an initial intense phase of parent training, Lucyshyn and colleagues (2002) have identified two supplementary phases of implementation support, including: (a) a transition phase that leads to self-sufficiency; and (b) a sustaining phase. In the transition phase, the goal is to build families’ self-efficacy and problem-solving capabilities in order to promote independence. In the sustaining phase, service providers arrange for periodic check-ups post-intervention to monitor progress, and offer additional training and support if necessary (Lucyshyn et al., 2002).

Although a number of studies on child sleep problems provided families with implementation support during the initial phase as noted above, only two studies provided families with support during the transition and sustaining phases (e.g., Weiskop et al., 2001; Weiskop et al., 2005). For example, Weiskop et al. (2001) taught parents how to use an abbreviated version of the partner support strategies developed by Sanders and Dadds (1993). Such partner support strategies are designed to teach communication and problem-solving skills and help parents to support one another. Additionally, Weiskop et al. (2001) conducted a review session towards the end of the study in which parents were taught how to gradually fade reinforcers. A longitudinal model of support such as this is likely to extend the generalization and maintenance of an intervention (Carr, Levin et al., 1999).
1.4.4 Ad-hoc Identification of Potential Obstacles to Generalization and Maintenance

Although the majority of the intervention studies reviewed were successful in reducing the overall bedtime disturbances and night waking in children with autism, a number of studies nevertheless showed brief regressions in disruptive behaviours. Such variability is not uncommon in research; however as Didden et al. (2002) noted when describing the limitations of their study, such regressions are often associated with unanticipated environmental or social obstacles such as hot weather, loud noises, sleeping in another bed during the weekend, the presence of a babysitter, or daytime sleeping. In some cases, researchers noted that intervention plans were difficult for parents to implement or were completely abandoned in the case of child illness (e.g., Christodulu & Durand, 2004; Durand & Christodulu, 2004; Durand et al., 1996; Wolf et al., 1964).

In these studies, the obstacles were identified post-intervention rather than prior to or during the intervention. Consequently, the obstacles interfered with the ongoing success of the intervention, by diminishing the parents’ ability to carry out the intervention over time. These limitations suggest the importance of assessing or identifying social and environmental obstacles prior to or during the implementation of the intervention and to plan for generalization to new people (e.g., babysitter) and settings (e.g., another bed) that the child and family may encounter. For example, if prior to the intervention researchers learn that the family uses a babysitter once a week, or that the child sleeps in another bed during the weekend, such obstacles can be assessed and integrated into the intervention plan in order to encourage generalization. Additionally, the anticipation or identification of potential obstacles pre-intervention or during, rather
than post-intervention and building support around such obstacles is likely to increase parents’ maintenance of intervention strategies over time (Lucyshyn et al., 1997).

1.5 Methodological Strengths

A review of the studies described above reveal a number of methodological strengths, including: (a) the use of experimental research designs (e.g., Christodulu & Durand, 2004; Didden et al., 2002; Durand, 2002; Durand & Christodulu, 2004; Piazza et al., 1997; Weiskop et al., 2005); (b) an emphasis on empirically-based interventions (e.g., Didden et al., 2002; Durand et al., 1996; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964); and (c) the measurement of specific sleep and parent satisfaction outcomes (Christodulu & Durand, 2004; Durand & Christodulu, 2004; Durand et al., 1996; Weiskop et al, 2001; Weiskop et al., 2005).

1.5.1 Use of Experimental Research Designs

Experimental research designs are used for the controlled testing of cause-and-effect relationships, and are often described as the most rigorous of all research designs due to their high internal validity. Over half of the studies reviewed used experimental research designs to document the efficacy of sleep interventions in children with autism. Researchers used two types of experimental research designs: (a) single-subject research designs such as multiple baseline designs and withdrawal designs; and (b) group designs with randomized trials.

1.5.1.1 Single-subject Research Designs

A number of studies conformed to concurrent or nonconcurrent multiple baseline designs across participants (e.g. Christodulu & Durand, 2004; Didden et al., 2002; Durand, 2002; Durand & Christodulu, 2004; Weiskop et al., 2005). In the concurrent design, all participants began baseline at the same time. In the nonconcurrent design,
participants were randomly assigned to different baseline lengths that were determined prior to the study. An advantage of using a multiple baseline design is that it is an experimental design and therefore allows for cause-and-effect relationships. Additionally, multiple baseline designs are particularly useful when the intervention produces a long-lasting effect or it is not possible or tolerable to return the behavior to baseline conditions (Neuman & McCormick, 1995), such as in the case for a sleep intervention.

In addition to a multiple baseline design, two studies used an embedded withdrawal design with one participant (Didden et al., 2002 and Christodulu & Durand, 2004). For example, in Christodulu & Durand (2004), the withdrawal of treatment during a family vacation resulted in the return of sleep disturbances to baseline levels. Reimplementation of the sleep restriction intervention resulted in decreases in both bedtime disturbances and night wakings. The withdrawal of treatment increases the internal validity of the design. However, as noted by Didden et al. (1998), parents may be reluctant to return to baseline following the effective treatment of a challenging sleep problem.

1.5.1.2 Group Randomized Trial

A group randomized trial is an experimental group design that involves the random allocation of members of an identifiable group (i.e. children with autism) to different interventions in order to compare the effectiveness of each intervention. For example, Piazza et al. (1997) used a group randomized trial to compare two behavioural sleep interventions: FBRC and bedtime scheduling. One group of seven children was assigned to the FBRC intervention, and a second group of seven children was assigned to bedtime scheduling. The results of the study indicated that the sleep problems of the
children in the FBRC group improved significantly as compared to the group receiving only bedtime scheduling. One of the primary advantages of using a group randomized trial is that it allows for a more powerful demonstration of treatment efficacy.

1.5.2 Emphasis on Empirically-based Interventions

Empirically-based interventions are those that have been shown by prior research to be effective. Across the studies reviewed, the majority of the studies utilized non-graduated extinction to improve sleep problems in children with autism (Didden et al., 2002; Durand et al., 1996; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964). Based on the Chambless criteria for treatment efficacy (Chambless & Hollon, 1998; Lonigan, Elbert & Johnson, 1998), non-graduated extinction is accepted as a “probably efficacious” intervention for sleep problems in children with autism (Schreck, 2001) and a “well-established” intervention to treat sleep problems in typically developing children (Mindell, 1999).

Because research in the area of sleep problems in children with autism is still in its infancy, other behavioural interventions reviewed (such as bedtime routines, bedtime scheduling, sleep restriction, graduated extinction, graduated withdrawal and FBRC) have not been identified as “well established” or “probably efficacious” interventions for sleep problems in children with autism (Schreck, 2001). However, the research on typically developing children has identified graduated extinction and scheduled awakenings as “probably efficacious” and bedtime routines as “promising” interventions (Mindell, 1999).

1.5.3 Measurement of Specific Sleep and Parent Satisfaction Outcomes

Researchers measure treatment outcomes in order to define the overall “success” of an intervention. In the studies reviewed, the treatment outcomes most commonly
measured were related to levels of problem sleep behaviour and included, “number of bedtime disruptions,” “number of night wakings,” and “number of nights child slept alone.” Most studies solely relied on parent diaries to measure treatment outcomes, while one study (Christodulu & Durand, 2004) used actigraphy combined with parent diaries. Additionally, some researchers had parents complete the Albany Sleep Problems Scale (Durand, 1998), a 46-item questionnaire designed to assess the type and severity of sleep problems prior to the intervention and then again upon completion of the intervention (e.g., Christodulu & Durand, 2004; Durand & Christodulu, 2004).

A few studies also measured parent satisfaction with treatment outcomes by administering a social validity questionnaire (i.e., whether the goals of treatment, the intervention techniques that are used, and the outcomes that are achieved are acceptable, relevant, and useful to the family involved). For example, Christodulu and Durand (2004) and Durand and Christodulu (2004) used the Parental Sleep Satisfaction Questionnaire (Christodulu, 2000) which assesses parental satisfaction with the child’s current sleep pattern and is conducted prior to intervention and then repeated following intervention. Additionally, Weiskop et al. (2001) and Weiskop et al. (2005) included a comprehensive assessment of social validity at the end of the study. In these two studies social validity was ascertained using a modification of the Griffin and Hudson (1978) Program Evaluation Questionnaire, in which parents answered three open-ended questions regarding what parents liked best and least about the intervention, and parts they would change. The remainder of the questions were answered using a 5-point Likert scale and included questions regarding the level of parental approval of techniques used during the intervention, the amount of improvement seen in child’s sleep and behaviour in general,
the amount improvement in parental stress levels, and if they would recommend the program to others.

1.6 Methodological Limitations

A review of the studies also revealed a number of methodological limitations, including: (a) the insufficient collection of interobserver agreement data; (b) the limited use of multiple measures to assess treatment outcomes; (c) the insufficient collection of long-term follow-up data; and (d) the lack of replication studies with primary behavioural interventions, each of which are described below.

1.6.1 Insufficient Collection of Interobserver Agreement Data

Interobserver agreement is used to assess the degree of agreement among observers recording a given behaviour. A number of studies did not collect data on interobserver agreement. Although some studies used direct measures to evaluate the data, such as actigraphy (Christodulu & Durand, 2004), in most cases parents were generally responsible for implementing the treatment strategies and collecting the data in the form of sleep diaries, with no independent reliability checks conducted (e.g., Didden et al., 2002). Additionally, at least one parent in a family (e.g., father) would either refuse to collect data or be unable to do so. This resulted in only one parent collecting the data, thus allowing for no opportunity for independent verification by a second parent (e.g., Didden et al., 2002; Durand et al., 1996). Although data collection by both parents is ideal, it is frequently not possible such as in the case of single-parent families (Durand et al., 1996). Despite this, there is still some research to support the reliability of parent completed sleep diaries (Durand & Mindell, 1990). For example, Durand and Mindell (1990) videotaped their participant’s bedtime routine on a weekly basis to assess both the reliability of the data collected and the parent’s compliance to the intervention and found
no systematic bias. Nevertheless, the collection of interobserver agreement data is important to control the quality of sleep data collected and will strengthen the internal validity of the study.

1.6.2 Limited Use of Multiple Measures to Assess Treatment Outcomes

In addition to the measurement of specific sleep outcomes and parental satisfaction following treatment, there is value in expanding measures to additionally assess: (a) treatment integrity (i.e., parents’ accuracy in implementing intervention strategies); (b) the contextual fit of the intervention plan; and (c) changes in child and family quality of life as a result of the intervention (Lucyshyn et al., 2002). None of the studies reviewed included these measures. By expanding treatment outcome measures such as in these four studies, it is more likely that researchers will be able to gather, in a more meaningful way, the information necessary to evaluate the overall success of the sleep intervention and improve the effectiveness, acceptability and contextual fit of behavioural sleep interventions (Lucyshyn et al., 2002).

Of the four studies that collected social validity data, only Christodulu and Durand (2004) did so during baseline, intervention and follow-up. Two studies collected such data solely at the end of the study (e.g., Weiskop et al., 2001; Weiskop et al., 2005) and one study did so at the beginning of the study and again at the end of the intervention (e.g., Durand & Christodulu, 2004). Although there is merit in evaluating the social validity of the intervention at the beginning and again at the end of an intervention, it is much better to conduct such a formative evaluation throughout the intervention process. As noted by Schwartz and Baer (1991), such an ongoing formative evaluation during the intervention will allow the researchers to review the intervention plan to improve its acceptability and feasibility, and the parents’ satisfaction of child and family outcomes.
1.6.3 Insufficient Collection of Long-term Follow-up Data

Although most of the studies conducted a follow-up of 1-6 months, there was an overall lack of long-term follow-up, with few studies following children for any period of time over one year. Additionally, there were three studies that did not collect any follow-up data, including Wolf et al. (1964), Durand et al. (1996) and Durand and Christodulu (2004). Weiskop et al. (2001) and Weiskop et al. (2005) were the only two studies to conduct a follow-up at 1 year post-intervention.

Sleep problems in children with autism are persistent and often long in duration. For example, Robinson and Richdale (2004) found that the average duration of sleep problems was 7-9 years across two groups of children with and intellectual disability; 27.7% and 44% of children in each group also had autism. Additionally, sleep problems tend to dissipate for a period of time and then later return (Christodulu & Durand, 2004). Therefore, it is important to evaluate sleep interventions a substantial amount of time beyond direct treatment to assess the sustainability of treatment effects.

1.6.4 Lack of Replication Studies with Primary Behavioural Interventions

Another limitation is the lack of replication studies with primary behavioral interventions. Non-graduated extinction was the only intervention with any replication by different researchers (e.g., Didden et al., 2002; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964). Given the limited amount of available data and by the relatively weak research designs used, replication is necessary to clearly ascertain the efficacy of such behavioural interventions.
1.7 Synthesis: Toward a Model Clinical Intervention and Research Approach to Sleep Problems in Children with Autism

The clinical strengths and shortcomings of current evidence based practice in the amelioration of sleep problems in children with autism and other developmental disabilities offer interventionists direction for the development of a model clinical intervention approach. In such a model approach, interventionists would: (a) conduct assessments and design sleep interventions in close collaboration with family members; (b) use functional assessment procedures to guide the design of multicomponent interventions that include antecedent, teaching and consequence strategies; (c) ensure that sleep routines and intervention procedures possess a good contextual fit with the family; (d) provide initial training and support to the family in the home setting using behavioural parent training strategies; (e) offer maintenance support as necessary to ensure that parents are able to sustain the intervention over prolonged periods of time and to ensure the sustainability of improvements in child behaviour over time; and (f) identify other relevant sleep environments that the child may experience across his/her lifecycle and program for generalization. At the same time, the methodological strengths and limitations in the research also suggest a model approach to the design of research that would enhance the research’s internal, social and ecological validity. Such research would include: (a) the use of experimental designs, including single subject research designs or randomized control trials; (b) the use of empirically-based sleep interventions that are consistent with functional assessment results; (c) the use of multiple measures to assess treatment outcomes, including measures to assess child sleep problems, level of routine success, parent implementation fidelity, social validity, contextual fit and family quality of life; (d) the measurement of interobserver agreement for quantitative measures
of behaviour change; (e) the collection of long-term follow-up data (up to at least one year) to assess the sustainability of the sleep intervention; and (f) across the long-term, direct replication with different children and families, as well as systematic replication across different researchers.

As discussed below, features of such a model approach can be found in Positive Behaviour Support (PBS).

1.8 Positive Behaviour Support

Positive Behaviour Support (PBS) is a collaborative, assessment-based approach to the development of effective, individualized behaviour support plans for individuals who engage in problem behaviour, including children with autism and other developmental disabilities (Carr, Dunlap, Horner, Koegel, Turnbull & Sailor, 2002; Carr, Horner, Turnbull, Marquis, McLaughlin & McAtee, 1999). Within this approach, behaviour support plans emphasize the use of evidence-based proactive and educative strategies to achieve meaningful and durable improvements in the focus individual’s behaviour and quality of life. In family contexts, interventionists take into consideration family perspectives and family systems when developing interventions and supports (Fox, Dunlap & Powell, 2002; Koegel, Koegel, Boettcher, Brookman-Frazee, 2005; Koegel, Koegel & Dunlap, 1996; Lucyshyn et al., 2002). Accordingly, PBS plans may include family-focused supports that aim to strengthen the family as a whole.

PBS is currently viewed as an emerging, evidence-based practice that addresses the behavioural and quality of life needs of children, youth, and adults with developmental disabilities as well as children and youth at risk for or with identified behaviour disorders (Carr et al., 1999; Scotti & Kennedy, 2000). Its empirical and philosophical foundations include applied behaviour analysis, the normalization and
inclusion movement, and person centred values. (Carr et al. 2002). From an empirical perspective, PBS is inextricably linked to applied behaviour analysis, the science of behaviour change (Carr et al., 2002; Lucyshyn et al., 2002). The design of PBS plans is informed by behavioural principles such as establishing operations, stimulus control, functions of behaviour, positive and negative reinforcement, and positive and negative punishment (Chance, 1998; Miltenberger, 1997). PBS researchers use a variety of research designs, including single subject methods, group design methods and qualitative methods for the purpose of advancing the scientific foundation of the approach (Carr et al., 2002; Risley, 1999; Schwartz & Olswang, 1996). PBS research emphasizes ecological validity; that is, research is conducted in natural settings with natural treatment agents such as parents and educators (Carr et al., 2002; Dunlap, Fox, Vaughn, Bucy, & Clarke, 1997; Meyer & Evans, 1993). Equal attention is given to the requirements for internal, external and social validity (Carr et al., 2002; Carr et al., 1999; Dennis, Williams, Giangreco, & Cloninger, 1993; Risley, 1996; Sands, Kozleski, & Goodwin, 1991; Schalock, 1990, 1996; Turnbull & Turnbull, 1999).

Philosophically, PBS is linked to the normalization and inclusion movements. Through the practice of PBS, practitioners seek to help individuals gain access to the same opportunities as others and to be fully included in family, school, and community life (Carr et al., 2002). Person centred values that PBS practitioners strive to demonstrate in their professional interactions with persons with challenging behaviour as well as with family members, educators, and other professionals involved in the process of behavioural assessment and intervention and include humility, respect, and empowerment (Eber, 1997; Lucyshyn et al., 2002; VanDenBerg & Grealish, 1998).
Over the past 15 years, PBS research in school and community settings has documented the efficacy of the approach (Blair, Umbreit, & Bos, 1999; Blair, Umbreit, & Eck, 2000; Carr et al., 1999; Carr et al., 2002; Carr & Carlson, 1993; Clarke, Dunlap & Vaughn, 1999; Clarke, Worcester, Dunlap, Murray, & Bradley-Klug, 2002; Duda, Dunlap, Fox, Lenti, & Clarke, 2004; Dunlap, Foster-Johnson, Clarke, Kern, & Childs, 1995; Dunlap & Fox, 1999; Reeve & Carr, 2000; Shukla, Kennedy, & Cushing, 1999; Vaughn, Wilson & Dunlap, 2002). Research with families has provided preliminary evidence of PBS’ effectiveness, acceptability and sustainability when implemented in natural family contexts with parents as interventionists (Barry & Singer, 2001; Buschbacher, Fox & Clarke, 2004; Dunlap & Fox, 1999; Feldman, Condillac, Trough, Hunt & Griffiths, 2002; Frea & Hepburn, 1999; Galensky, Miltenberger, Stricker, & Garlinghouse, 2001; Koegel, Stiebel & Koegel, 2004; Lucyshyn, Albin, & Nixon, 1997; Lucyshyn et al., 2002; Lucyshyn et al., 2007; Moes & Frea, 2000; Moes & Frea, 2002; Vaughn, Clarke & Dunlap, 1997; Vaughn, Dunlap, Fox, Clarke, & Cucy, 1997; Vaughn et al., 2002).

1.9 A Family Centred, PBS Approach to Intervention and Research with Children with Autism and Sleep Problems

Taken as a whole, the clinical features of a PBS approach and the methods and standards that characterize exemplary PBS research are consistent with the design of a model clinical and research approach to sleep problems in children with autism. PBS builds from the clinical and methodological strengths evident in the research on sleep problems in children with autism, including: (a) the use of assessment and intervention in typical home settings with family members as interventionists; (b) the use of functional assessment to guide intervention planning; (c) the use of initial parent training and
therapist support; (d) the design of multicomponent interventions; (e) the use of experimental research designs; and (f) an emphasis on empirically-based interventions. There are also features of PBS that can be said to address some of the clinical and methodological limitations identified in the research, including: (a) the development of collaborative partnerships with families; (b) the design of interventions that possess a good contextual fit with the child’s family; (c) the maintenance support that aims to build parent resilience in the face of common obstacles to sustainability and durability; (d) the attention to the promotion of generalization; (e) the use of multiple measures to evaluate treatment outcomes; and (f) the collection of long-term follow-up data. According to Carr et al. (2002), effective, meaningful, acceptable, and sustainable outcomes are more probable if all of these features of PBS are integrated into a behavioural intervention. In addition, research that is designed to evaluate the extent to which each of these outcomes is achieved will serve to further advance the internal, social, and ecological validity of an intervention approach to sleep problems in children with autism. By placing an emphasis on these features in future research on sleep problems in children with autism, it will likely result in more successful approaches to the behavioural interventions.

This study will use a family-centered PBS approach to the amelioration of sleep problems in children with autism that integrates evidence-based practices from the research on sleep problems in children with autism with the emerging evidence-based practices of PBS. The approach represents an adaptation of a family-centered, PBS approach described by Lucyshyn, Kayser, Irvin and Blumberg (2002); Buschbacher, Fox and Clarke (2004); and Binnendyk and Lucyshyn (2009) to the needs of families raising a
child with autism who engages in sleep problems in the home. The approach includes six core features, each of which are described below.

First, throughout the assessment and intervention process, the interventionist will work to build a collaborative partnership with family members that is aimed at overcoming the child’s problematic sleep behaviours (Kanfer & Grimm, 1980; Turnbull, Turnbull, Erwin & Sodak, 2006; Webster-Stratton & Herbert, 1993). Second, the intervention will focus on improving child behaviour within the activity setting of the bedtime routine in the home (O’Donnell, Tharp & Wilson, 1993). This is important because the activity setting has been identified as an ecological unit of analysis that may promote generalization and maintenance of treatment outcomes (Lucyshyn et al., 2004; O’Donnell & Tharp, 1990). Third, a functional assessment of sleep problems will be supplemented with a sleep assessment and family ecology assessment for the purpose of designing a behaviour support plan that will be not only technically sound, but contextually appropriate. Fourth, implementation training and support will be provided to the family members who will be directly supporting the child in the sleep routine. This will include a written behaviour plan, direct training with the child, modeling and coaching with parents, and problem solving discussions (Sanders & Dadds, 1993). Fifth, multiple measures of treatment outcomes will be assessed, including children’s improvements in sleep behaviour, as well as parents’ implementation fidelity and ratings of social validity and goodness-of-fit (Kincaid, Knoster, Harrower, Shannon & Bustamante, 2002). The last feature involves the use of strategies designed to promote long-term outcomes. These strategies include the identification of obstacles to maintenance and the design of a relapse prevention plan to prepare for such obstacles.
Additionally, to assess long-term outcomes, measurement may be extended to months and/or years post intervention.

1.10 Research Problem

The study evaluated the efficacy and acceptability of a family-centered, PBS approach to sleep problems in children with autism that integrated the evidence-based practices from applied behaviour analysis research on sleep problems with the emerging evidence-based practices of PBS. A 4-year-old child with autism experiencing sleep problems and his family participated in the study. The present study addressed the following questions:

1) Is there an association between the implementation of a family-centered PBS plan and improvements in sleep behaviour in a child with autism, including: (a) the percentage of intervals of bedtime disturbances; (b) the frequency of night wakings; (c) the duration of night wakings; (d) latency to falling asleep; and (e) the percentage of steps successfully completed in the bedtime routine?

2) Is there an association between the family-centered, PBS approach and improvements in family quality of life as measured by The Beach Centre Family Quality of Life Survey (Beach Centre, 2001)?

3) How do participating parents rate the social validity of the family-centered, PBS approach to sleep problems?

4) How do participating parents rate the goodness-of-fit of the behaviour support plan to the bedtime routine and overall family ecology?
2 Chapter: Research Design and Methods

2.1 Participant Recruitment

After an initial proposal of the study was approved by my research committee, I waited to obtain approval from the Behavioural Research Ethics Board (BREB). After providing additional provisions regarding the study, approval from BREB was obtained.

APPENDIX A

To recruit a child with autism and sleep problems, I contacted school districts, non-profit agencies serving children with autism, and advocacy and support groups for families of children with autism and provided them with information about the study and the criteria for participation. Agency representatives forwarded a letter of initial contact (see Appendix A) to families whom they believed met the criteria for the study.

The criteria for participation were: (a) a diagnosis of autism according to DSM-IV guidelines; (b) the presence of bedtime disturbances, night waking, and/or co-sleeping problems; (c) the child not currently taking any sleep medication; and (d) the child not having a history of seizures or other medical conditions that may be related to his or her sleep problems. Additional criteria pertaining to the parents included: (a) their ability to speak English; (b) the parents not perceiving themselves as being in “crisis” due to the child’s problem behaviours (i.e., requesting or receiving crisis intervention services); and (c) the parents agreeing to allow an observer to videotape the bedtime routine.

If a family was interested in participating in the study, they were encouraged to contact me (student researcher) or Dr. Joseph Lucyshyn (principal investigator) to set up a prescreening interview (see Appendix B).

At the start of the participant recruitment process, I forwarded a copy of the letter of initial contact to the family’s behavioural consultant and asked her to pass it along to potential families that met the criteria, and if families were interested, to encourage them
to contact me or Dr. Joseph Lucyshyn (see Appendix B). Shortly afterward, the mother of a young child with autism spectrum disorder (ASD) contacted me by email expressing her interest in the study and we set up a time to conduct a prescreening interview over the telephone. During the prescreening interview, I discussed the purpose of the study and reviewed the criterion for participation. The mother expressed a continued interest in the study, and we made arrangements to review and sign the initial screening interview consent forms, conduct the initial screening interview, and subsequent pilot observations. Shortly afterward, I met with the mother and father at the family’s home and they signed the consent forms to participate in an initial screening interview and pilot observations (see Appendix C). During the initial screening interview, I asked the mother and father a number of questions to determine the nature and severity of the child’s sleep problems. Following the initial screening interview I conducted two subsequent pilot observations of the family sleep routine. The results of the initial screening interview and observations indicated that the child and family met the study’s criteria. Accordingly, the family was invited to participate in the study and a consent form for study participation was given to the parents for their signature. Following these activities, the family agreed to participate in the study, signed the consent forms and was enrolled in the study (see Appendix D).

2.2 Participant

One 4-year-old-child and his family participated in the study. The child was diagnosed with pervasive developmental disorder, not otherwise specified (PDD-NOS) at the age of 3 years, 5 months, in June 2009. The child was a bright, talkative and energetic boy who enjoyed listening to music, going to the park, and watching Scooby Doo.

The participant was an only child in a Canadian family, and lived at home with his mother and father. The child’s father was an engineer and worked away from home.
for 3-4 week periods at a time, returning for 1-2 weeks in between. The child’s mother
was a stay-at-home mother and also the primary parent participant throughout the
research and intervention process.

The child started an ABA-based program in September 2009 under the
supervision of a certified behavioural consultant, and received approximately 8 to 10
hours a week of behavioural intervention at home and in the community. The child also
attended a half-day preschool 3 days a week from 9:15 am to 11:45 am. In addition, he
received support from a speech and language pathologist, and a nutritionist
approximately once a month. The child also received support from an occupational
therapist approximately once a week until October 2010.

2.3 Setting

The setting was a bedtime routine envisioned by the child’s parents, which took
place in their home in the early evening. The envisioned bedtime routine and its elements
were defined in collaboration with the child’s parents. In order to define the envisioned
bedtime routine, an interview was conducted with the child’s parents in the family’s
home. The bedtime routine was defined according to the six elements of an activity
setting as defined by O’Donnell, Tharp, and Wilson (1993). These elements were:
(a) the time and place of the routine; (b) the people present; (c) the material resources
used; (d) the tasks and how they were organized; (e) child and family-centred goals,
values, and beliefs that informed the routine, and (f) the common patterns of interaction
that would occur during the routine (Gallimore et al., 1989, O’Donnell, Tharp & Wilson,
1993). The child’s parents also were encouraged to create a bedtime routine that was: (a)
consistent with the child’s characteristics; (b) consistent with the family’s goals and
values; and (c) sustainable over time.
The envisioned bedtime routine was summarized into a one-page operational definition. The child’s parents reviewed the definition, minor edits were made, and the finalized version was given to the parents. The operational definition of the envisioned bedtime routine is presented in Table 2.1.

This operational definition was used in each of the phases (i.e., baseline and intervention) to guide the mother through the bedtime routine. The operational definition was also used when creating the steps completed data sheet (see Appendix E).

2.4 Measurement and Instrumentation

2.4.1 Dependent Variables

The study included eight dependent variables directly related to sleep: (a) percentage of intervals of bedtime disturbances; (b) latency in minutes to termination or successful termination of the routine; (c) percentage of steps successfully completed in the bedtime routine; (d) average latency to falling asleep per week; (e) average number of night wakings per week; (e) average duration of night wakings per week; and (f) number of nights in which co-sleeping occurred per week. Additionally, the study included four dependent variables, not directly related to sleep: (a) parent implementation fidelity of the PBS plan; (b) average parent rating of the social validity of the support; (c) average parent index of the support plan’s goodness-of-fit; and (d) average rating of the family’s quality of life. The study also included a debriefing questionnaire to assess the mother’s experience of participating in the study.

2.5 Measurement

A multiple probe technique (Horner & Baer, 1978) was used to monitor the dependent variables and to document the implementation of the independent variable. In a multiple probe technique, intermittent measures or “probes” are gathered during each
Table 2.1  Operational Definition of Envisioned Bedtime Routine

**Time and Place**

1. The routine will begin between 6:30 and 6:45pm.
2. The routine will last approximately 30-45 minutes. Child will go to bed between 7:15 and 7:30pm.
3. Child will stay in his room until 6:30am.
4. The persons present will be mother and son.
5. Material resources will be: (a) toothbrush and toothpaste; (b) child’s bed; (c) bedding; (d) pajamas; (e) comfort items (i.e., his fuzzy blanket); and (f) children’s books.

**Child’s Tasks**

1. Child’s tasks are going upstairs when asked, undressing, taking a bath, brushing teeth, going to his bedroom, putting on pajamas, sitting on the couch in his bedroom with his mother, choosing a book to read, and listening to 1-2 stories.
2. Child’s tasks also include getting into bed, staying in bed while his mother gets up, staying in bed while his mother leaves the bedroom and closes door, going to sleep and staying in his bedroom until 6:30am.

**Parent’s Tasks**

1. Mother’s tasks are to help her son complete the preparation steps, including prompting him to go upstairs, helping her son to take a bath, brush his teeth, dry off and put on his pajamas, including prompts to do these steps by himself.
2. Mother’s tasks also include prompting her son to sit on the couch in his bedroom, sitting on the couch with her son, offering her son a choice of books, reading 1-2 stories, prompting her son to get into bed, saying goodnight and giving her son a hug and/or kiss, getting up, dimming the light, leaving the room and closing the door.

**Child-centred Goals**

1. Child centred goals are: (a) for child to be able to go to sleep independently in his own bed; (b) for child to be able to be quiet, stay in bed and not play while in bed at night; (c) for child to get a good night’s sleep; and (d) for child to stay in his room until 6:30

**Family-centered Goals**

1. Family centred goals are: (a) for parents to have quality time in the evening together; (b) for mom to get a good night’s sleep; (c) for mom to be able to have a night off, and (d) for others to be able to put child to bed (including the child’s father and the babysitter).

**Patterns of Interaction**

1. Expected patterns of interaction include mother and father giving a 5 minute warning for bedtime, and child complying with mother’s and father’s requests without negotiating, and for child and parents to complete steps in bedtime routine in a relaxed and calm way.
These are referred to as “probe observation sessions.” Horner and Baer (1978) suggest that the use of a multiple probe technique is appropriate when prolonged baselines may be impractical or could have negative effects for the participants or the study. This design may also be more feasible when conducting research in family contexts with parents as implementers of the independent variable (Buschbacher, Fox, & Clarke, 2004; Clarke, Dunlap, & Vaughn, 1999; Fox, Vaughn, Dunlap, & Bucy, 1997; Horner & Baer, 1978; Lucyshyn, Albin, Horner, Mann, Mann, & Wadsworth, 2007).

Given the severity of the child’s behaviours during the bedtime routine, a multiple probe measurement procedure was deemed most appropriate.

2.5.1 Probe Observation Sessions of the Child Going to Bed and Falling Asleep

Probe observation sessions of the child going to bed and falling asleep were conducted at regular intervals, where possible, across each phase of the study (i.e., during baseline and intervention). During baseline, probe observation occurred once every 1 to 2 weeks across a 2-month period (December 2010 to January 2011). During intervention, probe observations occurred after a maximum of 4 training sessions, and typically occurred after 2-3 training sessions. Intervention probes were conducted across an 11-month period which included a one month break in June 2011 and a three month break from October to December 2011. Probe observation sessions of the child going to bed and falling asleep (hereafter referred to as “full” probe observation sessions) were recorded using a digital video camera, and captured the entire bedtime routine, including going to bed (i.e., relaxing activities before bed, having a bath, brushing teeth, putting on pajamas, and reading a story before bed) and falling asleep (i.e., parents saying goodnight, child getting into bed, laying down and falling asleep). Probe observation sessions were scheduled on a day that was convenient to the family and occurred during
the time of night envisioned for the bedtime routine by the family. On probe observation days, training and support activities did not occur.

To minimize physical and psychological risks to the child and the parents, prior to the initiation of probe observation sessions, a criterion level of problem behaviour for terminating the routine was collaboratively defined with the child’s parents (Carr & Carlson, 1993; Lucyshyn et al., 2007). The family and I identified both “untolerated” and “tolerated” problem behaviours that would require the termination of the routine. When any instance of untolerated problem behaviour was observed (i.e., high intensity behaviour), the routine was terminated. When three or five instances (dependent on the specific behaviour) of tolerated problem behaviour were observed (i.e., low to moderate intensity behaviour) the routine similarly was terminated. The operational definitions of tolerated and untolerated behaviour and the criterion level of problem behaviour for terminating the routine are described in Table 2.2.

During a probe observation session, I adhered to a protocol that had been used successfully in several previous studies using a PBS approach to behavioural interventions with families (e.g., Lucyshyn et al., 1997; Lucyshyn et al., 2007; Binnendyk & Lucyshyn, 2009). The protocol involved: (a) confirming the time and place of the probe observation session; (b) arriving approximately 15 minutes before the observation session and ensuring that all materials needed for the routine are present; (c) asking the child’s parents to review the operational definition of the envisioned routine; (d) placing the video camera in a position that ensured that the parent and child were in the field of vision; and (e) asking the parent to initiate the bedtime routine.
Table 2.2  Operational Definitions of Tolerated and Untolerated Behaviour

**Tolerated Behaviour**

**Fearful talk:** defined as fear-related statements and questions (stop after 5th instance)
(a) Examples include: “I’m scared” or “Are there monsters?”
(b) Non-examples: talking about monsters in play (e.g., “You be the monster!”), or talking about the good monster that guards the house and protects him, or commenting on monsters seen while watching television or in books.

**Verbal protest/defiance:** defined as protesting/refusing to accept “no” (stop after 5th instance)
(a) Examples: saying, “no,” yelling or screaming, “no!”, or “I don’t want to!” and refusing to accept “no” from parent such as screaming “I want it!”
(b) Non-examples:
   i. “no” in natural conversation (e.g., Mom asks “Do you like….” or “Can elephants really do that?”; or Mom asks for clarification, “Is that a….,” and child responds “No”), or during play (e.g., while playing hide and go seek with toys in the bath Mom asks, “Is he over here?”; and child responds, “No”, or Mom says “I’m going to eat your leg!”; child responds, “No, I’m going to eat your leg!”); no when a true choice is provided (e.g., Mom asks if he wants to finish the activity, and child responds “No”, or Mom asks if he wants his blanket, and child responds “No”)
   ii. when child restates reasonable requests/negotiates with parent in a polite tone of voice (e.g., Child asks if he can get a book from his Dad’s room, Mom says “no”, and child responds “But, I want a Daddy book” and Mom makes the call that this is not an unreasonable request and allows him to get a book).

**Crying:** defined as crying with tears
Non-examples: crying when the child gets hurt (stop after 3rd instance or after 3 minutes)

**Physical resistance:** defined as physically struggling against parental assistance to complete the task/steps in the routine (stop after 3rd instance)
(a) Examples: leaning away from parent, dropping to the floor, flailing arms and legs, turning away from parent or pushing parents hand away when parent tries to provide physical assistance.
(b) Non-examples: when child falls unintentionally while holding parent’s hand, and parent pulls child back up (e.g., while they are running together up the stairs); when parent picks child up or physically prompts him to follow through with a request; when parent is assisting child to complete non-preferred self-help tasks, rocking when child is on Mom’s lap.

**Elopement:** defined as leaving assigned area or remaining away from assigned area as defined in steps in routine (stop after 5th instance).
(a) Examples: running away from parent and/or assigned area, getting out of bed, leaving bedroom, and going downstairs during the routine.
(b) Non-examples: leaving with permission from parent (e.g., leaving bath to get a toy), leaving to use the bathroom, sitting up in bed

**Tantrum:** defined as dropping to the floor, flailing, accompanied by screaming and crying (stop after 3rd instance or after 3 minutes).
Table 2.2 Continued Operational Definitions of Tolerated and Untolerated Behaviour

Untolerated Behaviour

*Physical aggression:* defined as any negative physical contact toward another person that causes distress, pain or injury *(stop after 1st instance).*
(a) Examples include kicking, hitting, scratching, pinching and biting
(b) Non-examples include: silly or playful behaviour such as nibbling on the parent’s arms

*Destructive behaviour:* defined as any negative physical contact towards objects that may cause physical damage *(stop after 1st instance).*
(a) Examples include kicking doors, throwing objects, or knocking objects off of counters/surfaces
(b) Non-examples including: climbing/reaching up to get an item and it gets knocked off, crashing cars during play

During a probe observation session, I videotaped for a minimum of 3 minutes or until the routine was successfully completed. If the criterion level of problem behaviour, previously defined with the family, was reached any time after the 3 minutes, the probe observation session was immediately terminated. If the criterion level of problem behaviour occurred before 3 minutes, I continued to videotape for 3 minutes and then the routine was terminated. A minimum of 3 minutes was required to obtain sufficient data to compare baseline and intervention phases (Carr & Carlson, 1993). Termination of the routine took place upon: (a) the first instance of untolerated problem behavior; or (b) the third or fifth instance (depending on the behaviour) of tolerated problem behaviour. The decision to terminate the routine was made by me or the child’s parents. When the routine was terminated due to the criterion level of problem behaviour, the video camera was turned off and I provided the parent with assistance as necessary.

2.5.2 Probe Observation Sessions of the Child Falling Asleep

In addition to probe observation sessions of the child going to bed and falling asleep, which captured the entire routine, the mother collected an additional 1 to 2 probe observation sessions (here after referred to as “partial” probe observation sessions),
which captured only the falling asleep portion of the routine (i.e., mother saying goodnight, child getting into bed, laying down and falling asleep). These data were typically gathered on two consecutive nights immediately after the probe observation of the child going to bed and falling asleep. The purpose of these additional observations was to: (a) establish the stability of improvements in the child’s behaviour at a fading step before advancing to the next fading step; and (b) document the child falling asleep portion of the bedtime routine in the absence of an observer other than family members.

2.5.2.1 Equipment and Materials

Probe observation sessions were videotaped using a digital video camera and then later scored by me and a second observer in Dr. Joseph Lucyshyn’s lab in the Faculty of Education at the University of British Columbia. The digital video recordings were directly downloaded from a digital videotape on the hard drive of the computer and a DVD of the file was created. The digital videotapes and DVDs were stored in a locked cabinet in Dr. Joseph Lucyshyn’s lab. A computer software media player program (i.e., Windows Media Player) was used to code child behaviour (i.e., percentage of intervals of bedtime disturbances, latency to termination or successful completion of the routine) and parent behaviour (i.e., parent implementation fidelity of the PBS plan). When coding a probe observation session, I used the built-in “count-up” clock feature in Windows Media Player to track the intervals (i.e., 10 second or 30 second intervals). Data sheets and a pencil were used to record the occurrence and/or nonoccurrence of child and parent behaviour.
2.6 Operational Definitions of Dependent Variables

2.6.1 Percentage of Intervals of Bedtime Disturbances

*Bedtime disturbances* were defined as problem behaviour that occurred during the bedtime routine. A partial-interval recording system using 10 second intervals was used to measure the “occurrence” or “non-occurrence” of problem behaviour. If problem behaviour was observed at any time during any 10 second interval, the interval was scored as an “occurrence.” If problem behaviour was observed multiple times within an interval, it was still scored as a single occurrence. If problem behaviour was not observed during a 10 second interval, the interval was scored as a “non-occurrence.” The percentage of intervals of bedtime disturbances (P<sub>BD</sub>) was calculated using the following formula: \( P_{BD} = \frac{N_{BD}}{\text{Total Intervals}} \times 100 \). \( N_{BD} \) refers to the number of bedtime disturbances.

2.6.2 Latency in Minutes to Termination or Successful Completion of the Routine

The child’s problem behaviours during the bedtime routine were distressing to his mother and father. For this reason, an observation and data recording strategy similar to one developed by Carr and Carlson (1993) was used. A criterion level of problem behaviour for terminating the routine was collaboratively defined with the child’s parents (see Table 2.2 above). The criterion balanced the parent’s goal of having their son participate in the bedtime routine with the ethical need to ensure physical safety and minimize psychological risk.

*Latency to termination* of the bedtime routine because of a criterion level of problem behaviours was defined as the number of minutes that elapsed between the initiation of the routine and: (a) the first instance of untolerated behaviour; or (b) the third to fifth instance (depending on the behaviour) of tolerated problem behaviour. *Latency to*
successful completion of the routine was defined as the number of minutes to completion of all critical task steps in the routine without the criterion level of problem behaviours occurring at any step of the routine.

Either the child’s mother or I made the decision to terminate an observation because of problem behaviour. When the frequency of problem behaviour met the criteria for termination, I prompted the mother to stop the routine. When the routine was terminated due to the criterion level of problem behaviour, the video camera was turned off and I provided the mother with assistance as necessary. When I was not sure if the criteria for terminating the routine was met (e.g., how many times the child protested “No!”) I continued to videotape until I was certain that the criterion was met. In this event I determined the latency in minutes to the criterion level of problem behaviours by observing the videotape and evaluating the sequence of problem behaviours exhibited by the child during the bedtime routine.

If the criterion for terminating due to problem behaviours did not occur, the routine continued until the routine was completed (i.e., until the child fell asleep). If the bedtime routine was completed successfully, I used the probe observation session’s data file time mark to record the total time of the routine.

2.6.3 Percentage of Steps Successfully Completed in the Bedtime Routine

Steps in bedtime routine were defined as those steps that the child’s parents identified and described as necessary to complete the bedtime routine. The steps in the bedtime routine were separated into two categories: going to bed steps and falling asleep steps. Going to bed steps included the child: (a) walking upstairs; (b) undressing; (c) taking a bath; (d) brushing his teeth; (e) going to his bedroom; (f) putting on his pajamas; and (g) sitting and listening to a bedtime story. Going to sleep steps included the child:
(a) receiving a hug and/or a kiss goodnight; (b) getting into bed; (c) turning off the light beside his bed; (d) laying down; (e) falling asleep; and (f) staying in bed until 6:30 am.

Using a checklist of the steps and a definition of the criterion level of problem behaviour (see Table 2.2 above), I recorded whether a step was successfully completed, not completed, or an opportunity to engage in the step was not provided (e.g., the parent did not offer to read the child a bedtime story). A “successful” step was completed when the child completed the behavioural requirements of the step and the criterion for termination due to problem behaviour was not reached during that particular step. In this case, I recorded each step as it was completed in the routine, up to the step of falling asleep. To measure if the last step in the bedtime routine (i.e., staying in bed until 6:30 am) was successfully completed, the mother recorded the time of awakening in the sleep diary. I called the mother the morning after the observation probe and she reported these data to me. These data were then included in the calculation of steps completed. In contrast, if, during any step, the criteria for termination due to problem behaviour were reached, the step was considered “unsuccessful” and the routine was terminated. When this occurred, I recorded the number of steps successfully completed before termination of the routine. The percentage of steps successfully completed ($P_{SC}$) in the bedtime routine was calculated using the following formula: $P_{SC} = N_{SC}/\text{Total Steps} \times 100$. $N_{SC}$ refers to the number of steps successfully completed.

2.6.4 **Average Latency in Minutes to Falling Asleep per Week**

*Latency to falling asleep* was defined as the number of minutes that elapsed between the parents placing the child into bed and saying, “Time to go to sleep” and the child falling asleep. The mother determined that the child was asleep when his eyes were closed (if he was facing her) and he was no longer making any movements. Data with
respect to latency in minutes to falling asleep was recorded by the mother using a semi-
structured sleep diary (see Appendix F). I then used these data to calculate the average 
latency to falling asleep for each week. A week was defined as a period of 7 consecutive 
days, starting with Sunday and continuing through to Saturday. Average latency to falling 
asleep ($A_L$) over a week was calculated using the following formula: $A_L = S_L/N_L$. $S_L$ 
refers to the sum of the latencies and $N_L$ refers to the number of latencies being averaged.

2.6.5 Average Number of Night Wakings per Week

Night wakings were defined as any instance in which the child woke after having 
initially fallen asleep and called out for his mother and/or got out of his bed at night. Data 
with respect to number of night wakings was recorded by the mother using the semi-
structured sleep diary. I then used these data to calculate the average number of night 
wakings that occurred each week. A week was defined as a period of 7 consecutive days, 
starting with Sunday and continuing through to Saturday. Average number of night 
wakings ($A_{NW}$) over a week was calculated using the following formula: $A_{NW} = 
S_{NW}/N_{NW}$. $S_{NW}$ refers to the sum of the night wakings and $N_{NW}$ refers to the number of 
night wakings being averaged.

2.6.6 Average Duration of Night Wakings per Week

Using the semi-structured sleep diary, the mother recorded, in minutes, the 
approximate duration of each night waking. I then used these data to calculate the average 
duration of night wakings that occurred each week. A week was defined as a period of 7 
consecutive days, starting with Sunday and continuing through to Saturday. Average 
duration of night wakings ($A_D$) over a week was calculated using the following formula: 
$A_D = S_D/N_D$. $S_D$ refers to the sum of the durations and $N_D$ refers to the number of 
durations being averaged.
2.6.7 Number of Nights Co-sleeping Occurred per Week

Co-sleeping was defined as anytime the child slept in the same bed or the same room as a parent for a period of more than five minutes. Data with respect to co-sleeping was recorded by the mother using a semi-structured sleep diary (see Appendix F). I then used these data to calculate the number of nights of co-sleeping that occurred each week. A week was defined as a period of 7 consecutive days, starting with Sunday and continuing through to Saturday. The number of nights of co-sleeping that occurred per week was calculated by tallying the number of nights that co-sleeping occurred to obtain a total for each week.

2.6.8 Parent Implementation Fidelity of PBS Plan

Parent implementation fidelity (i.e., “treatment integrity”) was defined as a parent’s accurate implementation of the PBS strategies described in the behaviour support plan. Following the design of the behaviour support plan, the PBS strategies were operationally defined (see Table 2.3 below). To aid in accurate scoring, examples and non-examples of accurate use were provided. Approximately 26% of the child’s intervention sessions were scored for parents’ accurate use of support strategies. Using a partial interval recording system (see Appendix G), the mother’s behaviour was scored as the percentage of intervals of implementation fidelity ($P_n$). The length of the interval was 30 seconds. During an interval, if the parent was observed using one or more strategies accurately, I scored the interval as “accurate.” If the parent was observed making one of more errors during an interval, I scored the interval as an “error.“ I did so even if the
Table 2.3  Operational Definitions of PBS Strategies

**Warnings for transitions:** Warnings for transitions include using a timer and/or giving verbal warnings before transitioning to a new activity.

- **(a)** Examples: “Two more minutes of TV, then we’re going upstairs”
- **(b)** Non-examples: “Time to go upstairs!”

**Visual Schedule:** A visual schedule is a set of pictures that communicates a series of activities (i.e., steps in the bedtime routine) or the steps of a specific activity (e.g., steps in washing hands). The use of a visual schedule is scored if the parent shows the child the schedule. The use of a visual schedule is also scored if the parent prompts the child to look at what activity next or to remove a completed activity.

**Large amount of maternal attention:** A large amount of maternal attention is when the mother provides 5-10 minutes of attention, cuddling and affection to the child before bed.

- **(a)** Examples: the mother sitting and cuddling with the child on the couch downstairs while reading books, watching television, doing quiet activities or talking about their day together
- **(b)** Non-examples: mother preparing dinner in the kitchen and doing periodic check-ins while child watches television on the couch

**Calming/soothing activities before bed:** Activities that promote a relaxed state in the child. The use of calming/soothing activities is scored if the parent engages the child in quiet activities before bed and avoids “academic” tasks (i.e., tasks that are cognitively demanding and, for the most part, in the acquisition phase of learning for the child).

- **(a)** Examples: reading a preferred book to the child on the couch, watching a preferred television show
- **(b)** Non-examples: while reading, the parent asks, “What letter comes before R?”, or “What does that spell?”, expecting the child to attend to non-preferred books before bed

**Gradual fading:** The parent gradually and systematically fades out of the child’s bedroom in stages. The use of gradual fading is scored if the parent does not verbally ask or physically move beyond the current step or move to a previous step while the child is falling asleep.

- **(a)** Examples: if the current fading step is sitting on the couch, the parent sits on the couch while the child falls asleep
- **(b)** Non-examples: if the current fading step is sitting on the couch, the parent leaves the child’s bedroom, or if after the child requests for the mother to come back, she lays in bed beside him

**Contingency maps:** A contingency map shows the child the pathways of appropriate and inappropriate behaviour and the consequences that will follow for appropriate and inappropriate behaviour. The use of contingency maps is scored if the parent reviews the contingency map with the child before going upstairs for a bath (e.g., while sitting on the couch downstairs), before the child goes to bed (e.g., while sitting on the couch in the child’s bedroom) and/or before the criterion to termination due to problem behaviour is reached.
Table 2.3 Continued Operational Definitions of PBS Strategies

Positive contingency statements: A positive contingency statement is a verbal cue that communicates to the child what the desired behaviour is and what he will get after performing the desired behaviour (i.e., “First [behavior], then [reinforcer]”).

(a) Examples: the parent uses both parts of the contingency statement (e.g., to get the child out of the bath, the mother says “First stand up, then we’ll do a frog jump!”)
(b) Non-examples: the parent only uses part of a contingency statement (e.g., child says “I want the sailboat”, and parent replies, “First get out of the tub”); the parent uses a reverse contingency statement (e.g., “You’ll get a frog jump if you get out of the bath”); the parent uses a negative contingency statement (e.g., “Get out of the tub, or I’ll pull the plug!”); or the parent uses contingency statement during significant problem behaviour.

Behavioural momentum: Behavioral momentum is a behavioral strategy that entails making requests that are easy for the child (i.e., high-probability requests) before making requests that are more challenging or difficult (i.e., lower-probability requests) to increase compliance. Requests may follow a pattern, for example, easy-easy-easy-hard.

(a) Examples: “Touch your nose!” (easy), “Count to 10” (easy), “Turn around” (easy), “Get out of the bath” (hard)
(b) Non-examples: “How do you spell Vancouver?” (hard), “Get out of the bath” (hard)

Safety signals: A safety signal is a verbal cue that communicates to the child when a mildly aversive event will be terminated, and when a preferred event will occur again.

(a) Examples: parent indicates a duration of time or number of instances left of a non-preferred activity (e.g., “Only two more, then you’re finished!” or “One more minute, then we’re all done!”); parent indicates a duration of time before returning to check-in on child (e.g., “Go to sleep, I’ll be back in two minutes!”)
(b) Non-examples: parent indicates duration of time before transitioning from a preferred activity to another preferred, a less preferred or a non-preferred activity (e.g., “One minute, then we’re getting out of the bath!”); parent reassures the child (e.g., “Go to sleep, you’ll be okay! I love you!”)

Choices: A choice is when the parent allows the child to make a decision during the bedtime routine. The use of choice is score if the parent uses controlled choices (i.e., “Do you want [X] or [Y]?”), choices where the child can indicate “yes” or “no” (“Do you want your blanket in bed?”), or general choices (i.e., “What do you want?”). For example, the parent may give the child a choice of: (a) whether he wants to take a bath at night or the next morning (if he is tired or hasn’t eaten properly); (b) which nights he would like to wash his hair; (c) which bath he would like to use (e.g., the “little bath” in the bathroom upstairs or the “big bath” in the bathroom in the parent’s bedroom); (d) which toothbrush and toothpaste to use; (e) what kind of jump he would like to do to get out of the bath; (f) which books to read before bed; or (g) which prize he would like in the morning for falling asleep and staying in bed.

(a) Examples: “Do you want your green toothbrush or the electric toothbrush?”, “What toys do you want in the bath?”
(b) Non-examples: when the parent offers a choice that isn’t truly a choice or when a demand is stated as a question (e.g., “Is it okay if I brush your teeth?”, “Can you put on your pajamas?”)
Table 2.3 Continued Operational Definitions of PBS Strategies

**Pre-correction statements**: A pre-correction statement is a proactive reminder given to the child of what appropriate behavior is expected. Use of verbal pre-correction statements is scored when the statement is made *before* problem behavior occurs. Pre-correction statements may include the parent reminding the child: (a) to ask for more time to engage in a preferred activity; (b) to ask for help with difficult/self-help tasks; (c) to ask for a break from a difficult/self-help task; (d) what he can do if he wakes up at night, and the relaxation strategies he can use; and (e) to ask for attention or for the parent to come back after leaving the bedroom.

(a) Examples: “Remember, if you want more time, you can say ‘Can I have two more minutes?’”
(b) Non-examples: parent indicates it’s time to turn off the television and the child screams, and in response the parent says “Remember I want you to use nice words” (statement given *after* problem behaviour has occurred)

**Teaching relaxation strategies**: Teaching relaxation strategies involves teaching the child to take deep breaths and perform modified progressive relaxation exercises (i.e., squeezing and relaxing muscle groups), and teaching self-soothing strategies (e.g., “I’m safe, I can go back to sleep”, “Dad’s gone, it’s ok”) using direct instruction (i.e., modeling the words about his own sense of calmness, modeling deep breathing and squeezing and relaxing muscles) and having the child practice/rehearse the strategies before bed.

(a) Examples: while reading the social story, the parent pauses to practice some relaxation strategies “Squeeze your face like a monster!”, “Show me three deep breaths”
(b) Non-examples: the child is jumping on the bed and the parent says “Wow, you’re really getting all your energy out before bed!”

**Teaching using whole task instruction**: Teaching using whole task instruction involves providing the minimum amount of assistance necessary for the child to complete each step in the routine correctly. Whole task teaching is used particularly during difficult/self-help tasks including: (a) washing hands, (b) dressing and undressing; (c) brushing teeth; and (d) washing in the bath. The use of whole task instruction is scored when the parent assists the child *before* the child has a chance to make an error.

**Contingent reinforcement**: Contingent reinforcement is reinforcement that is delivered immediately (up to 3 seconds) following desired behaviour. Contingent reinforcement includes: (a) verbal praise; (b) physical affection; and (c) tangible items. Verbal praise may include an evaluative or descriptive comment. Contingent reinforcement is scored when the parent provides praise, physical affection and/or tangible items for: (a) transitioning to a new activity; (b) complying with routine-related tasks; (c) for lying down quietly in his bed during the current step in the fading strategy; and (d) in the morning for going to bed, falling asleep, going back to sleep at night by himself, and staying in his room. The use of contingent reinforcement is not scored when verbal praise or a tangible item is given *after* the child engages in problem behaviour or makes an error.

(a) Examples: “Great job putting on your pajamas! You did it all by yourself!”, “Thanks for getting in the bath! Here are some bubbles!”
(b) Non-examples: “You can do it!” “Oops, that’s okay, try again!”
Honoring polite requests: Honoring polite requests involves the parent accepting polite requests made by the child, including requests for: (a) more time to engage in a preferred activity; (b) help with difficult/self-help tasks; (c) a break; (d) the parent to give him attention; or (e) for the mother to come back. The limit for requesting more time to engage in any specific activity is once (i.e., child can ask for more time only once while watching television). Further requests made by the child will not be honored, and are not scored as errors.

(a) Examples: The child is watching television, and the timer beeps indicating it’s time to go upstairs, the child asks “Can I have two more minutes?” and the mother responds, “Of course, you can have two more minutes.”

Non-examples: The child is watching television, and the timer beeps indicating it’s time to go upstairs, the child asks “Can I have two more minutes?” and the mother responds, “It’s late, not tonight.”

Ignoring and redirecting minor problem behavior: If the child engages in minor problem behavior, the parent ignores the behavior (i.e., refrains from making comments or discussing the behavior) and redirects the child back to the current task/next activity in the routine. Ignoring attention-seeking behavior may include the parent stating that the problem behavior is not acceptable in a neutral tone of voice (e.g., “That’s not okay) and removing or minimizing her attention for a short period of time. Redirection includes: (a) stating a contingency statement; (b) stating a controlled choice; (c) prompting/physically assisting the child to complete the task; (d) prompting the child to make a polite request for attention, help or a break; and/or (d) diverting the child’s attention.

(a) Examples: while watching television on the couch, the child starts licking the mother and in response, the mother says “Remember, if you have a calm body, you can watch television.”

(b) Non-examples: while watching television on the couch, the child starts licking the mother and in response, the mother says “What’s that all about? That’s silly!”

Ignoring and redirecting major problem behavior: If the child engages in major problem behavior during the falling asleep steps (e.g., getting out of bed), or gets out of bed during the night, the parent actively ignores and redirects the child back to bed by: (a) guiding him from the back; (b) avoiding making eye contact; (c) not talking to him or making any comments regarding his behavior; (d) waiting beside the child’s bed until he is calm without physically touching him. When the child is calm, the parent re-states the safety signal, if appropriate, and returns to the current fading step.

Parent implemented other plan strategies accurately. If the parent was not observed using any strategies during the 30 sec interval, the interval was scored as a “nonoccurrence.”

The percentage of intervals of parent implementation fidelity ($P_{PI}$) was calculated using the following formula: $P_{PI} = N_{PI}/Total Intervals \times 100$. $N_{PI}$ refers to the number of intervals of “accurate” use of strategies.

2.6.9 Average Parent Rating of the Social Validity of the Support Effort

A social validity questionnaire was used to assess the acceptability of intervention goals, procedures and outcomes. A revised version of the questionnaire designed by
Lucyshyn and colleagues (1997) was used (see Appendix H). The mother rated each of the 10 items on a Likert scale from 1 to 5 (1= disagree; 5= agree). The questionnaire was completed by the mother twice during the intervention phase. After the mother completed the questionnaire, an average rating across the 10 items was calculated and used as formative rating of social validity. During these calculations, ratings for items 3 and 7 were converted to reflect the same interpretation as the other 10 items (i.e., 1=disagree, 5=agree). Additionally, across the two evaluations an average was calculated to form a summative rating of social validity.

2.6.10 Average Parent Index of the Support Plan’s Goodness-of-Fit

A “goodness-of-fit” assessment in the form of a questionnaire was used to evaluate whether the support plan was a good fit with the ecology of the family (Albin et al., 1996). A revised version of the questionnaire designed by Albin et al. (1996) was used (see Appendix I). The questionnaire included 11 questions related to features of goodness-of-fit: (a) goals and expectations; (b) support roles; (c) congruence to lifestyle; (d) implementation effort; and (e) sustainability. The mother completed the questionnaire twice during the intervention phase. The mother rated each item using a 5-point Likert scale (1=a little; 5=a lot). After the mother completed the questionnaire, an average rating across the 11 items was calculated and used as a formative index of goodness-of-fit. During these calculations, ratings for items 7 and 9 were converted to reflect the same interpretation as the other 9 items. Additionally, across the two evaluations an average was calculated to form a summative index of goodness-of-fit.

2.6.11 Average Rating of the Family’s Quality of Life

The family’s perception of their overall quality of life was measured by administering The Beach Centre Family Quality of Life Survey (Beach Centre, 2001). The
survey is comprised of 25 items that assess five quality of life domains: (a) family interaction; (b) parenting; (c) health and safety; (d) family resources; and (e) support for the family members with disabilities (see Appendix J). Psychometric evaluations of the survey have shown that it possesses excellent reliability (Cronbach alpha of .94 on importance ratings and .88 on satisfaction ratings) and concurrent validity (correlation coefficients of .68 and .60 \( p < .001 \)) with well-established measures of quality of life (Hoffman, Marquis, Poston, Summers & Turnbull, 2006; Park et al. 2003). The mother rated each of the 25 questions on a 5-point Likert scale (1= very dissatisfied; 5= very satisfied). After each survey, an average rating across the items in each of the domains was calculated and used as a formative rating of the family’s quality of life. The mother completed the survey during baseline and at the end of the intervention phase.

**2.6.12 Debriefing Questionnaire**

A brief, debriefing questionnaire comprised of nine open-ended questions was used to assess the mother’s experience and perspective regarding: (a) her expectations related to the study and its goals; (b) delays and obstacles encountered; (c) pace of the study; and (d) the interventionist’s response to the mother’s introduction of additional interventions (see Appendix K). In addition, a final set of questions asked the mother to share any advice she would give to families and feedback she would offer to interventionists in relation to participating in a family-centred PBS intervention focused on sleep problems. The mother completed the questionnaire at the end of the intervention phase.
2.7 Interobserver Agreement (IOA)

2.7.1 Observer Training

In order to obtain interobserver agreement data, I trained another graduate student in the Faculty of Education at the University of British Columbia (UBC) to score the data as described above. Training materials provided to the observer included guidelines for scoring data sheets containing operational definitions, examples and non-examples of child and parent behaviour and a scoring protocol. The observer was trained to: (a) use the computer in the lab to code data using Windows Media Player; and (b) score data sheets for data collection. A sample of probe observation sessions from the baseline phase was used to practice coding percentage of intervals of problem behaviour and percentage of steps successfully completed. Data collection for percentage of intervals of bedtime disturbances and for percentage of steps successfully completed commenced once at least 85% interobserver agreement was achieved across two consecutive observation sessions of the bedtime routine.

Once the PBS plan was designed and detailed operational definitions were developed for coding parent implementation fidelity (see Table 2.3), observer training for coding parent implementation fidelity began. A sample of probe observation sessions from the intervention phase was used to practice coding parent implementation fidelity. Data collection for parent implementation fidelity commenced once at least 85% interobserver agreement was achieved across two consecutive observation sessions of the bedtime routine.

2.7.2 Interobserver Agreement Procedures

In order to measure interobserver agreement, the observer and I independently observed the same video recordings of probe observation sessions, which were chosen at
random, and measured each of the following variables for “agreement”: (a) percentage of intervals of bedtime disturbances; (b) latency to termination or successful completion of the bedtime routine; (c) percentage of steps successfully completed in bedtime routine; and (d) parent implementation fidelity of PBS plan strategies.

IOA for each of the variables was calculated using the following formula: \( P_A = \frac{N_A}{N_A + N_D \times 100} \). \( N_A \) refers to the number of agreements. IOA checks were completed on 30% of the probe observation sessions, balanced across baseline and intervention.

### 2.7.2.1 IOA for Percentage of Intervals of Bedtime Disturbances

The observer and I independently observed the same video recordings of probe observation sessions and scored the number of 10 second intervals in which: (a) problem behaviours are observed during the bedtime routine (“an occurrence”); (b) problem behaviours are not observed during the bedtime routine (a “non-occurrence). An “agreement” occurred when both the observer and I recorded an occurrence or a non-occurrence of problem behaviour during the same 10 second interval. The average agreement for percentage of intervals of bedtime disturbances across all probe sessions was 97% (range, 97 – 98%).

### 2.7.2.2 IOA for Latency in Minutes to Termination or Successful Completion of the Bedtime Routine

The observer and I independently observed the same video recordings of probe observation sessions and scored: (a) latency in minutes to termination of the bedtime routine; or (b) latency in minutes to successful completion of the bedtime routine. An “agreement” occurred when both the observer and I recorded the same time (within a margin of +/- 5 seconds) that the criterion level of problem behaviour was reached (i.e.,
the first untolerated behaviour, or the third to fifth tolerated behaviour) or the same time when the routine was successfully completed (i.e., child falling asleep). The average agreement for latency in minutes to termination or successful completion of the bedtime routine across all probe sessions was 100% (no range).

2.7.2.3 IOA for Percentage of Steps Successfully Completed in Bedtime Routine

The observer and I independently observed the same video recordings of probe observation sessions and, using a checklist that described each step, scored the number of: (a) steps successfully completed during the bedtime routine (an “occurrence”); (b) steps that were not successfully completed due to problem behaviour (a “non-occurrence”); and (c) steps that were not successfully completed because the opportunity was not presented, although required (a “no opportunity non-occurrence”). An “agreement” occurred when both the observer and I recorded an occurrence, a non-occurrence or a no opportunity non-occurrence during the same step of the routine. The average agreement for percentage of steps successfully completed across all probe sessions was 100% (no range).

2.7.2.4 IOA for Parent Implementation Fidelity of PBS Plan Strategies

The observer and I independently observed the same video recordings of probe observation sessions and scored the number of 30 second intervals in which: (a) the parent displayed accurate use of the strategies outlined in the family’s PBS plan (an “occurrence”); (b) the parent displayed inaccurate use of the strategies outlined in the family’s PBS plan (an “erroneous occurrence”); or (c) the parent was not observed using any of the strategies outlined in the family’s PBS plan (a “non-occurrence”). An “agreement” occurred when both the observer and I recorded an occurrence, an erroneous
occurrence or a non-occurrence of a strategy during the same 30 second interval. The average agreement for parent implementation fidelity of PBS plan strategies across all probe sessions was 87% (range, 85 – 90%).

2.8 Research Design

A single-subject case study design was used for this study. A multiple probe technique, as described above, was used when gathering data (Horner & Baer, 1978). The design consisted of two phases: baseline and intervention. Three baseline probe observation sessions were conducted to establish stable levels of problem behaviour during the bedtime routine. After sufficient baseline data were collected to document the stability of the behaviour, the intervention phase was introduced and data continued to be collected during this phase.

A single-subject case study design was selected for three reasons: (a) an experimental design such as a multiple baseline design across families was not feasible due to the time constraints involving in completing a Master’s thesis; (b) the single subject case study design offered a reasonably rigorous alternative given that a traditional, experimental design was not feasible; and (c) a withdrawal or reversal design was not suitable due to practical and ethical considerations (Barlow, Blanchard, Hayes, & Epstein, 1977). Although a single-subject case study is not a true experimental design, it is a relatively strong design that can greatly contribute to the development of scientifically usefully information (Kazdin, 1992). According to Kazdin (1992), single-subject case study designs offer a strong basis for drawing scientifically valid inferences about the impact of an intervention. Specifically, characteristics such as, continuous assessment of objective data, stable levels of performance before and after intervention,
and immediate and large treatment effect to help rule out specific threats to internal validity in a manner similar to a true experimental design (Kazdin, 1992).

2.9 Independent Variable

The independent variable was a family centred, PBS approach to a behavioural sleep intervention that consisted of four key components: (a) a comprehensive assessment (including a functional assessment and a family ecology assessment); (b) PBS plan development; (c) implementation plan development; and (d) implementation support. The independent variable was implemented under the supervision of Dr. Joseph Lucyshyn (principal investigator).

2.10 Comprehensive Assessment

Prior to developing a PBS plan, the following assessments were conducted with the family: (a) a functional assessment; and (b) a family ecology assessment. The information obtained from each assessment was then used to develop a comprehensive PBS support plan in collaboration with the family that was effective, acceptable and contextually appropriate.

2.10.1 Functional Assessment

The functional assessment was conducted by using a Functional Assessment Interview (FAI) form and a Functional Assessment Observation (FAO) form (O’Neill, Horner, Albin, Sprague, Storey & Newton, 1997). The FAI took place in the home and was approximately 60 minutes in length. The parents were asked to answer the questions posed in the FAI form in as much detail as possible, and to provide relevant examples or anecdotes, where applicable. After the completion of the FAI, in collaboration with the parents, we developed hypotheses about: (a) the functions of the problematic sleep
behaviour; (b) events that triggered the behavior; and (c) the events or situations that increased the likelihood of positive sleep behaviour.

After a consensus was reached by me and the family, a FAO was conducted during the bedtime routine to confirm the hypotheses formulated from the FAI. Using the FAO form, I documented the time the problem behaviour occurred, the antecedents and consequences of the problem behaviour and my perception of the function of the behaviour during the event in which the problem behaviour took place. The videotaped sessions taken during baseline, as later described below, were used to collect these data.

The functional assessment observation confirmed the hypothesis that the problem behaviors that occurred during the bedtime routine served the functions of escape and attention. The results of the functional assessment of the bedtime routine are summarized in the summary statements and competing behavior pathways diagrams below.

2.10.2 Family Ecology Assessment

Following the functional assessment, a family ecology assessment was conducted to gather information about the family’s ecology and the bedtime routine for the purpose of designing an intervention that was contextually appropriate from the family’s perspective. The family ecology assessment took place in the family’s home and was approximately 90 minutes in length. The family ecology assessment consisted of two parts: (a) an assessment of family sleep routines, including natural variations across the year; and (b) a broad family ecology assessment that identified the family’s strengths, resources, social supports, sources of stress and goals. The results of the interview are summarized in Table 2.4 below.
### Family Ecology Assessment

<table>
<thead>
<tr>
<th>Child and Family Strengths</th>
<th>Family Resources and Social Supports</th>
<th>Sources of Stress</th>
<th>Child and Family Goals</th>
</tr>
</thead>
</table>
| **Mother and father:**    | - are committed to each other, their family, and to helping their child  
- communicate well with each other  
- support each other’s decisions, including decisions involving their son  
- share mutual goals and values  
- have a good sense of humour and like to laugh  
- agree that family time is very important and that they make time to do activities together  
- appreciate and love each other  
- have an established routine | - the family receives support from a child psychologist, speech therapist and occupational therapist  
- the child receives behavioural intervention  
- the child attends preschool  
- the family’s nanny intermittently lives with the family  
- the family has a cleaning lady who comes in once every two weeks | - the child’s problem behaviour, including his screaming and aggression, especially when going to bed  
- receiving negative feedback from school regarding her son’s behaviour;  
- the father is worried that they are not making progress with their son, even with all the support they are receiving  
- when the child or parents don’t get enough sleep and are tired  
- the parents trying to balance family time, time to themselves, and time alone  
- the mother has a very busy schedule, and that it’s exhausting keeping her son on his schedule, running around to all of his appointments  
- the child demands a lot of care and supervision  
- at the end of the day the father finds it difficult to come home to chaos, especially when he has been solving problems all day at work, it’s hard to come home and do the same thing, and that he just wants to come home to a relaxing, peaceful environment | - for sleep to be blissful, part of the daily routine, and not something to struggle against  
- for their son to be able to settle himself and fall asleep independently  
- for their son to be able to go to the washroom at night and be able to go back into bed without wandering around  
- for their son to realize that sleep is for important  
- for their son to have a good sleep so he can function during the day  
- for their child to fall asleep independently so they can have valuable time to themselves in the evening  
- to raise their son to be self-sufficient, responsible, intelligent and emotionally balanced  
- for their son to fit in, have friends over, but also have a unique personality  
- to be supportive of their son’s decisions and interests and help him follow through with those decisions  
- to peace and harmony in their family  
- in the future to be still married, living together, and be in a "good space" together |
| **Child:**                | - has an amazing memory, loves to learn and is a quick learner, is persistent, loves to laugh, is a lot of fun to be around, is energetic, wants to please people; and is good at gymnastics  
- adds another dimension to the parents relationship, gives the mother and father the opportunity to develop more common goals, and helps to solidify them as both a team and a family unit, brings joy to the family, allows the mother and father see things from a new perspective because of the way he describes things, and the nuances in the way he sees the world, makes parents excited when he learns new things | - the family has a strong extended family support network  
- both the mother and father have a large social network, including friends from work, old school friends, friends of their nanny, and friends in the community that have children the same age as their son  
- the mother and father have a good relationship and support each other, have fun together, and solve problems together |"
2.11 PBS Plan Development

Results from the functional assessment and the family ecology assessment were used to design, in collaboration with the parents, a technically sound and contextually appropriate PBS plan for the bedtime routine. This process included three steps: (a) building a summary statement and competing behaviour pathways diagrams; (b) identifying strategies to address the problematic sleep behaviours; and (c) selecting strategies that were likely to be both technically sound and contextually appropriate.

2.11.1 Building a Summary Statement and Competing Behaviour Pathways Diagram

Results from the functional assessment were first used to develop summary statements and competing behaviour pathways diagrams for the bedtime routine (Horner et al., 2000; Lucyshyn, Kayser et al., 2002). Initially, two separate summary statement and competing behaviour diagrams were created to address the different steps of the routine (i.e., going to bed, and falling asleep steps respectively), and the corresponding functions of the child’s behaviour that occurred primarily in each of these steps. Each diagram outlined the following four features of the sleep problem: setting events; antecedent triggers; problem behaviours; and maintaining consequences (i.e., function of the problem behaviours). The diagrams also identified desired behaviours for the sleep routine and acceptable alternative replacement behaviours. In addition, the diagrams included a summary of logically linked strategies that addressed each of the features of the problem behaviour. The completed diagram, including the summary statement, competing pathways diagram and logically linked strategies for the going to bed steps is presented in Table 2.5a and Table 2.5b below (see Table 2.5a and Table 2.5b). The completed diagram for the falling asleep steps is presented in Table 2.6a and Table 2.6b.
Table 2.5a  
Summary Statement and Competing Pathways Diagram: Problem Behaviour Associated with Going to Bed

When Mom or Dad asks N to: (a) transition from a preferred activity to a less preferred activity (i.e., transition from watching television to going upstairs, transition from playing in the bath to getting on his pajamas); (b) perform a difficult/non-preferred self-help task (i.e., put on pajamas/pull-up, wash his hands, brush his teeth, wash his hair); or (c) perform an “academic” task (i.e., attend to non-preferred books, answer difficult questions); during the bedtime routine, N is likely to ignore the request, verbally protest, physically protest, act silly and/or run away in order to escape or temporarily delay the transition or task. When Mom or Dad repeats the demand, goes after N, and/or physically redirects/guides him, N may protest, physically resist support, try to run away or drop to the floor and scream/cry in order to either escape or temporarily delay the transition or the task. N’s problem behaviours in the bedtime routine are more like to occur because of a history of problem behaviour around bedtime and the parent’s tendency to use negative contingencies that elicit anxiety in N. N’s problem behaviours are more like to occur when there are unpredictable activities during the day, when N doesn’t eat properly throughout the day, when N is overtired, and/or when N engages in rambunctious play before bed.

<table>
<thead>
<tr>
<th>Setting Event(s)</th>
<th>Antecedent Trigger(s)</th>
<th>Problem Behaviour</th>
<th>Desired Behaviour</th>
<th>Maintaining Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of problem behaviour around bedtime</td>
<td></td>
<td>N verbally protests</td>
<td>Praise for successful transition and complying with requests</td>
<td></td>
</tr>
<tr>
<td>Unpredictable activities during the day</td>
<td></td>
<td>Runs away</td>
<td>Tangible reward/preferred activity natural to the routine</td>
<td></td>
</tr>
<tr>
<td>When N doesn’t eat properly throughout the day</td>
<td></td>
<td>Physically protests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When N is overtired/has missed nap</td>
<td></td>
<td>Cries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When N engages in rambunctious play before bed</td>
<td></td>
<td>Tantrums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tendency of parents to use negative contingencies that elicit anxiety in N</td>
<td></td>
<td>Ignores request</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acts silly</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alternative Replacement Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>N asks for more time</td>
</tr>
<tr>
<td>N asks for help/break</td>
</tr>
</tbody>
</table>
Table 2.5b  PBS Plan: Problem Behaviour Associated with Going to Bed

<table>
<thead>
<tr>
<th>Setting Event Strategies</th>
<th>Preventative Strategies</th>
<th>Teaching Strategies</th>
<th>Consequence Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>If N is really tired or hasn’t eaten properly: (a) give him a choice of whether he wants to take a bath at night or the next morning; (b) provide more assistance for difficult/self-help tasks; (c) provide more choice; and (d) increase reinforcement for complying with requests</td>
<td>Provide N with opportunities to make choices throughout the routine. Give N a choice of: (a) which nights he would like to wash his hair; (b) which bath he would like to use; (c) which toothbrush, toothpaste and shampoo he would like to use; (e) what kind of jump he would like to do to get out of the bath; and (f) which books to read before bed.</td>
<td>Teach N to ask for more time before transitioning to the next activity (e.g., “Can I have two more minutes?”)</td>
<td>Provide N with descriptive praise contingent on transitioning to new activity and complying to requests to do the next step in the activity</td>
</tr>
<tr>
<td>Develop a visual schedule for activities in evening routine that include each of the steps/tasks that will be completed and reinforcers for completing each step</td>
<td>Use a contingency map to show N what he will receive if he completes steps/tasks in the routine cooperatively</td>
<td>Teach N to ask for help with difficult/non-preferred tasks (e.g., “Help please”, “I need help”)</td>
<td>Provide N with descriptive praise contingent on completing difficult/non-preferred self-help tasks with increasing independence (e.g., Wow! You found the back of your pajamas and put them on all by yourself!” You’re such a big boy!”)</td>
</tr>
<tr>
<td>Use a timer/verbally warn N of transitions to the next activity (e.g., to go upstairs to take a bath, to get out of the bath)</td>
<td>Use positive contingency statements (e.g. “If you get in the bath, you will get to choose a toy/bubbles!”, “First put on your pajamas, then I will read you a story!”)</td>
<td>Teach N to request a break during difficult/non-preferred tasks (e.g., “Can I have a break?”)</td>
<td>Provide tangible rewards/preferred activities natural to the routine contingent on positive behaviour (e.g., bubbles/toys for successfully getting in the bath)</td>
</tr>
<tr>
<td>Embed playful activities into transitions (e.g., have N pretend to be an airplane to go upstairs) and/or have N carry a preferred item to the next activity to ease the transition</td>
<td>Use pre-correction statements to remind N to ask for: (a) more time to engage in a preferred activity; (b) help with difficult/non-preferred tasks; and/or (c) a break from difficult/non-preferred tasks</td>
<td>Teach N new skills using whole task instruction by (a) providing the minimum amount of assistance necessary for N to complete each step in the routine correctly; (b) gradually fade your assistance without loss of his ability to do each routine step correctly; (c) provide praise contingent on improvement in step completion and independence; and (d) gradually fade praise as N consistently shows cooperation and independence</td>
<td>Honour N’s requests for more time, help or a break if he asks politely. N can ask for more time once during any given activity during the routine.</td>
</tr>
<tr>
<td>Engage N in calming/soothing activities before bed and avoid “academic”/cognitively demanding tasks (e.g., asking N to attend to non-preferred books and/or answer difficult questions)</td>
<td>Use a safety signal to let N know when he will be finished difficult/non-preferred tasks (e.g., “One more, then we’re all done!”)</td>
<td>If minor problem behaviours occur: (a) actively ignore the behaviour; (b) redirect N to the activity/task; and/or (c) prompt N to politely ask for more time, help, or a break.</td>
<td></td>
</tr>
<tr>
<td>Refrain from using negative contingencies throughout the day; instead, use natural positive contingencies to motivate cooperation during the day</td>
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</table>


Table 2.6a Summary Statement and Competing Pathways Diagram: Problem Behaviour Associated with Falling Asleep

When Mom leaves N’s bedroom at night, N will get out of bed, act silly, laugh/giggle and leave the bedroom. N also may engage in fearful talk, verbally protest, scream, cry and/or tantrum. Then Mom will tell N it’s time for bed, give him verbal feedback and physically guide him back to the room. This results in N gaining attention and Mom lying down and sleeping with him. N’s problem behaviours in the bedtime routine are more like to occur because of a history of problem behaviour around bedtime, anxiety about being alone in his room and a tendency of his parents to use negative contingencies that elicit anxiety in N. N’s problem behaviours are more like to occur when there are unpredictable activities during the day, when N doesn’t eat properly throughout the day, when N is overtired, and/or when N engages in rambunctious play before bed.

<table>
<thead>
<tr>
<th>Setting Event(s)</th>
<th>Antecedent Trigger(s)</th>
<th>Problem Behaviour</th>
<th>Maintaining Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of problem behaviour around bedtime</td>
<td>Mom leaves N’s bedroom</td>
<td>N gets out of bed Leaves room Acts silly Laughs/Giggles Fearful talk Verbally protests Screams Cries Tantrums</td>
<td>Mom gives N verbal feedback and repeatedly guides N back to his room</td>
</tr>
<tr>
<td>Unpredictable or no scheduled activities during day</td>
<td>When N doesn’t eat properly throughout the day</td>
<td>N asks for attention /reassurance N asks for Mom to come back</td>
<td>N gains Mom’s attention and Mom lies next to N until he falls asleep</td>
</tr>
<tr>
<td>When N is overtired</td>
<td>When N engages in rambunctious play before bed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tendency of the parents to use negative contingencies that elicit anxiety in N</td>
<td>Anxiety about being alone in his room</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Desired Behaviour**

- N stays in his bed and remains calm
- N falls asleep in his own bed
- N sleeps through night until 6:30 am

**Maintaining Consequence**

- Praise from Mom during the bedtime routine
- Praise in from Mom and Dad in the morning
- Tangible reward in the morning
Table 2.6b  
PBS Plan: Problem Behaviour Associated with Falling Asleep

<table>
<thead>
<tr>
<th>Setting Event Strategies</th>
<th>Antecedent Strategies</th>
<th>Teaching Strategies</th>
<th>Consequence Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide N with a large amount (5-10 minutes) of maternal attention before going to bed (e.g., having him sit on mom’s lap, hugging him, talking about going to bed) in order to decrease the value of mom’s attention when going to bed</td>
<td>Use a fading technique to gradually fade yourself out N’s bedroom in phases. The criteria for moving to the next phase is N is successfully falling asleep within 20 minutes, 2-3 nights in a row. Use positive contingency statements to facilitate cooperation (e.g., “Lie down and I’ll sit next to you”)</td>
<td>Teach N to fall asleep on his own, go back to sleep if he wakes up in the night, and stay in bed until 6:30 am Teach N to ask for attention Teach N to ask Mom to come back to his room Teach N relaxation (e.g., deep breathing, tensing and relaxing muscles) and self-soothing strategies (e.g., “I’m safe, I can go back to sleep”) using direct instruction (i.e., modeling the words about his own sense of calmness, modeling deep breathing, and praising him for using these strategies)</td>
<td>Provide N with descriptive praise contingent on N lying down quietly and staying in his bed (in a soft, soothing voice) Provide N with descriptive praise and a tangible reward in the morning contingent on N lying down quietly, staying in his bed, falling asleep and staying in his room until 6:30am (e.g., iPad) Honour N’s requests for attention, or for Mom to come back if he asks politely. If N engages in fearful talk, reassure him that he is safe (e.g., “There are no monsters. Go back to sleep”). If minor problem behaviour occurs: (a) actively ignore the behaviour; and (b) remind him of the contingency; and/or (c) prompt N to politely ask for attention/for you to come back. If major problem behaviour occurs (i.e., N gets out of bed/leaves room): (a) actively ignore the behaviour (walk N back to bed guiding him from the back, don’t make eye contact, talk to him or make any comments regarding his behaviour); (b) wait beside N’s bed until he is calm but don’t physically touch him; and (c) when he is calm, restate the safety signal if appropriate, and re-implement the fading technique. If N calls out or gets up in the middle of the night: (a) go and check in on him, let him know that he is safe and that he should go back to bed; and (b) re-implement the fading technique</td>
</tr>
<tr>
<td>Develop and read a social story to N each night before going to sleep describing where everyone sleeps, what will be expected of him, and what he can do if he gets worried or upset</td>
<td>Before N goes to bed, use pre-correction statements to remind N: (a) to ask for attention and/or for to you to come back to his room; and (b) of what he can do if he wakes up at night, and the relaxation strategies he can use</td>
<td>Place an alarm clock in N’s room to indicate when it is time to get up in the morning</td>
<td></td>
</tr>
<tr>
<td>Remove N’s daily nap/start N’s bedtime routine later so that he is so tired and it is easier for him to fall asleep on his own at night</td>
<td>Use a visual contingency to show N what will happen in the morning if he falls asleep and stays in his room until 6:30am (e.g., playing with the iPad) Use safety signals before leaving when you reach the check-in phase (e.g., “Go to sleep, I’ll be back in a minute to check on you”)</td>
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below (see Table 2.6a and Table 2.6b). The logically linked strategies from each of the competing behaviour pathways diagrams were consolidated in the finalized PBS plan (see Appendix L).

2.11.2 Identifying Strategies to Address Problem Sleep Behaviours

The PBS plan included four types of strategies to address each of the features identified above: (a) setting event strategies; (b) antecedent strategies; (c) teaching strategies; and (d) consequence strategies. When selecting strategies, emphasis was placed on strategies that had empirical support in the sleep problem and positive behavior support literature. Strategies are described below.

2.11.2.1 Setting Event Strategies

Setting event strategies were selected to: (a) eliminate or minimize the likelihood that a setting event would occur; (b) neutralize the effects of a setting event; (c) temporarily reduce or eliminate antecedent triggers when a setting event had occurred or was present; and (d) temporarily increase the value of reinforcers for target behaviours when setting events occurred (Horner, Vaughn, Day & Ard Jr., 1996). Evidence-based setting event strategies that were included as components of a PBS plan for a bedtime routine included: (a) the elimination of sleep during the day (i.e., removing naps), and starting the child’s bedtime routine later so that he was tired and thus fell asleep more easily; (b) providing a large amount of maternal attention before bed in order to decrease the value of the mother’s attention; (c) representing events pictorially in order to increase predictability of a routine (i.e., the development of a visual schedule to represent each of the steps of the bedtime routine); (d) using individualized and dynamic social stories to
Table 2.7  Social Story

I am very busy. I go to school and I play with my friends and run around. Busy people need their sleep. A good night’s sleep prepares you for the next day.

I need to get ready before I go to bed. Before I go to bed I take a bath. I get to play with toys in the bath. It is so much fun! In the bath I wash my face, I wash my hair and I brush my teeth. Now I am clean and I am ready to put on my pajamas!

After I get on my pajamas I get to read a story on the couch with Mom. I put on my pajamas all by myself!

After we read a story Mom says “It’s time for bed” and I get a hug and a kiss goodnight. I turn down the lights and get into my Diego bed. Then I lie down and put my head on my pillow. I sleep in my own room in my Diego bed. I sleep all by myself. I like sleeping in my Diego bed! I am a big boy!

Variation 1: If I’m quiet and stay in bed Mom will sit next to me and hold my hand or rub my back. I can sleep in my bed all by myself!

Variation 2: If I am quiet and stay in bed Mom will sit on the couch in my room. I can sleep in my bed all by myself!

Variation 3: If I am quiet and stay in bed Mom will sit by my bedroom door. I can sleep in my bed all by myself!

Variation 4: If I am quiet and stay in bed Mom will sit outside my bedroom door. I can sleep in my bed all by myself!

Variation 5: If I am quiet and stay in bed Mom will come in and check in on me every _____ minutes. I can sleep in my bed all by myself!

If I wake up at night I can shut my eyes and go back to sleep and snuggle with my blanket. I am a big boy! I can sleep in my bed all by myself!

When my clock says its 6:30 I can wake up and go see Mom and Dad. If I wake up before 6:30 I can read my books quietly or listen to a story.

If I sleep in my bed all by myself I get a surprise in the morning! I can watch videos of machines on YouTube or pick a gift from the special box. I am a big boy! I can sleep in my bed by myself! Mom and Dad will be so proud of me if I remember to stay in my own bed!

Note: Variation 1 through 5 represents the fading steps. When the parent read the social story, the fading step operating was included.

increase predictability, deliver information and clarify expectations at each phase of the fading process (for an example of a social story used, see Table 2.7 below); (e) providing sufficient warnings for transitions (e.g., using a timer, giving verbal warnings); (f) providing the child with more choice and increasing reinforcement for complying with requests if he was tired or had not eaten properly; (g) embedding playful but not
stimulating activities into transitions and/or having the child carry a preferred item to the next activity to ease the transition; and (h) engaging the child in calming/soothing activities before bed.

2.11.2.2 Antecedent Strategies

Antecedent strategies were used before problem behaviour occurred in an effort to prevent problem behaviour or elicit target behaviour (Smith & Iwata, 1997). Antecedent strategies included as components of the PBS plan were: (a) offering opportunities for the child to make choices throughout the routine (e.g., number of minutes to engage in a preferred activity before transitioning, which two nights each week he would like to wash his hair, and which toothpaste to use); (b) using pre-correction statements (e.g., reminding child to ask for more time to engage in a preferred activity, for help with self-help tasks, or for a break from non-preferred tasks; (c) using positive contingency statements (e.g., “First put on your pajamas, then you can choose a bedtime story!”); (d) using safety signals to communicate to the child when a mildly aversive event would be terminated (e.g., “One more, then we’re all done!” “Go to sleep, I’ll be back in two minutes!”); (e) using a fading technique to gradually fade out of the child’s bedroom in steps (see Table 2.8 for steps in gradual stimulus fading technique); (f) using visual contingency maps to depict what the child will receive for completing steps in the routine cooperatively and what will happen in the morning if the child is able to fall asleep at the current step of the fading technique and stay in his room until 6:30 am; and (g) placing an alarm clock in the child’s room to indicate when it was time to get up in the morning. These strategies were designed to decrease the aversiveness associated with the bedtime routine, decrease the likelihood of problem behavior, and increase the child’s
motivation to participate cooperatively in the steps of the bedtime routine (Miltenberger, 2006; Smith & Iwata, 1997).

### 2.11.2.3 Teaching Strategies

Teaching strategies included teaching functionally equivalent communication skills as a strategy for replacing problem behaviour and teaching independence in performing steps in the bedtime routine or target behaviours (Mirenda, MacGregor & Kelly-Keough, 2002; Carr & Durand, 1985). Teaching strategies included as components of the PBS plan varied depending on the function of the child’s behaviour. During the going to bed steps of the bedtime routine, the function of the child’s behaviour was primarily escape-driven, therefore alternative replacement behaviour for the child was to politely ask for: (a) more time to engage in a preferred activity before transitioning to the next activity (e.g., “Can I have two more minutes?”); (b) a break from difficult or non-preferred activities (e.g., “Break please”); and (c) help with difficult or self-help tasks (e.g., “Can you help me?”). During the falling asleep steps of the bedtime routine the function of the child’s behaviour was primarily attention-driven, therefore alternative replacement behaviour for the child was to politely ask for the mother to come back and give him attention (e.g., “Mom, come back!”). Whole task instruction, in which the parent provided the child with sufficient assistance to succeed with a task step and then

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Mother beside the child’s bed</td>
</tr>
<tr>
<td>2.</td>
<td>Mother on the couch in the child’s room</td>
</tr>
<tr>
<td>3.</td>
<td>Mother sitting inside the child’s room at the door with the door closed</td>
</tr>
<tr>
<td>4.</td>
<td>Mother sitting outside the child’s door with her back pushed up against a curtain</td>
</tr>
<tr>
<td>5.</td>
<td>Mother sitting outside the child’s bedroom in the hallway with the curtain closed</td>
</tr>
<tr>
<td>6.</td>
<td>Mother leaving the child’s bedroom and hallway just outside his bedroom and doing brief check-ins</td>
</tr>
</tbody>
</table>
gradually faded her assistance, was used to increase the child’s independence with self-help tasks. In addition, the mother used direct instruction methods to teach the child relaxation skills (i.e., deep breathing, modified progressive muscle relaxation) and self-soothing strategies (e.g., “I’m safe, I can go back to sleep”).

2.11.2.4 Consequence Strategies

Consequence strategies were used to strengthen positive behaviour and/or to weaken problem behaviour (Piazza, Fisher, Roane & Hilker, 1999). Evidence-based consequence strategies included in the PBS plan were: (a) the delivery of specific praise contingent on desired behaviour during the bedtime routine (e.g., delivering descriptive praise after the child successfully completed steps in the bedtime routine, delivering praise in a soft, soothing voice for lying down and staying in bed, delivering enthusiastic praise in the morning if the child stayed in his room until 6:30 am); (b) the delivery of a tangible reward or preferred activity contingent on desired behaviour during the bedtime routine (e.g., bath toys for going upstairs and getting in the bath cooperatively, playing games on the iPad, watching videos on YouTube); (c) honouring the child’s appropriate requests (e.g., to have more time, for the mother to come back); (d) actively ignoring attention-motivated minor problem behaviour, and prompting the child to request attention; (e) actively ignoring minor problem behaviour, and redirecting the child; (f) actively ignoring major problem behaviour during the falling asleep step of the routine (i.e., guiding the child back to bed from the back without making eye contact or comments regarding his behaviour); and (g) checking in on the child if he calls out or gets up in the middle of the night, telling him he is safe and that he should go back to bed, and re-implementing the fading technique.
2.11.3 Selecting Technically Sound and Contextually Appropriate Strategies

In order to ensure that the strategies identified for the PBS plan were not only technically sound but also had a good contextual fit with the family, the child’s parents and I assessed the strategies and retained only those that were likely to be necessary and feasible. The child’s parents and I also reviewed the information gathered from the family ecology assessment and adjusted the strategies to further enhance the contextual fit. See Appendix L for the full version of the finalized PBS plan.

2.12 Implementation Support Plan Development

Immediately following the development of the PBS plan for the bedtime routine, an implementation plan was developed that defined: (a) training materials and support activities; (b) roles and responsibilities; and (c) a timeline for completing the support process. The implementation support plan was a working document that was revised several times throughout the intervention process with the family.

2.13 Implementation Support

During the intervention phase, the mother was provided with a written PBS plan that described each of the behavior support strategies to be used during the bedtime routine. The mother also was provided with an implementation checklist during the intervention phase (see Appendix M). An implementation checklist is a succinct version (i.e., one to two pages) of the written PBS plan, composed of a list of each of the steps of the intervention (Lucyshyn & Albin, 1993). The checklist was used by the mother to self-monitor and self-manage the implementation of the support strategies contained in the PBS plan.

Training sessions during the course of the intervention included training activities such as modeling, role play, behavioural rehearsal, and problem solving discussions.
Table 2.9 presents an example of role play scenarios used with the mother during the intervention phase. Training and support sessions occurred one to two times a week for one to two hours in the family’s home at the natural time of the routine. A maximum of 4 training sessions occurred before conducting a full probe observation session. Typically, a probe observation occurred after 2 to 3 training sessions. Support was gradually faded as the mother became more capable at implementing the intervention herself.

Due to time limitations, only the intervention phase was completed. For this reason, the planned maintenance and generalization phase was not completed, as these are not included in the description of the independent variable.

2.13.1 Delays, Obstacles, and Solutions

During the study, several delays and obstacles were encountered. At several points during the intervention phase, the family asked to temporarily pause or take a break from implementation support and research activities. This resulted in delays in the intervention process. The family requested a pause or break for three reasons: (a) family vacations, holidays and social gatherings; (b) parent or child illness; and (c) during times of multiple changes occurring in the child’s or family’s life. These delays are briefly described below.

The first type of requested pause or break in the support and research process was due to family, social and holiday events. These included two extended family vacations during the summer months, visits to have dinner at the homes of extended family members living in the Lower Mainland, and preparations for and participation in the
Table 2.9  Role Play Scenarios

Scenario #1

You’re sitting on the couch with N, and would like to spend some quality time with him and start to calm him down before bed. It’s been a long day for N and his teachers let you know that he had a rough day at school. Although the TV is on, you notice that he’s having difficulty settling down for the night, and he’s climbing around and on top of you, and at times being a bit rough, sometimes copying what he’s seen on TV (e.g., licking your arm like Scooby Doo).

(a) What can you do now to redirect and prevent the problem?
(b) What could you have done prior to the problem so that it was prevented?

Scenario #2

N is in the bath and is enjoying playing with his favourite toy, and because N is such a smart and inquisitive boy, he’s asking you about how the toy works. You would like him to get out of the bath, and start getting him ready for bed. You tell him that his two minutes is up, and it’s time to put away his toys and pull the plug, and in response he continues to ask about the toy.

(a) What can you do now to redirect and prevent the problem?
(b) What could you have done prior to the problem so that it was prevented?

Scenario #3

N has just had a bath, and you’d like put on his Calendula cream, and for him to put on his pull-up before going into his room and putting on his pajamas. You pass him his pull-up and tell him to put it on, and while you’re opening the tube of Calendula, he goes to the sink and pulls out the Penatin cream, and sticks his finger in the tub.

(a) What can you do now to redirect and prevent the problem?
(b) What could you have done prior to the problem so that it was prevented?

Scenario #4

You’re sitting on the couch and reading a bedtime story to N before getting into bed. You ask him a few simple questions relating to the book that you know that he can answer, and he smiles and easily answers the questions. He is learning spelling in school, and you notice a teachable moment. You ask him a few harder questions, and he pauses for a long time, and sometimes gets them wrong.

(a) What can you do now to redirect and prevent the problem?
(b) What could you have done prior to the problem so that it was prevented?

Christmas holiday. In this case, support and research activities were rescheduled for after the social event or holiday. The second type of pause or break in the support and research process was due to child or parent illness. This type occurred more often in the Fall in October 2010 and November 2010. In this case, support and research activities were
suspended until the mother indicated that child or parent had completely recovered. The third type of pause or break was due to major transitions in the child’s or family’s life. In this regard, the mother informed me that she felt comfortable with only one change or major event at a time occurring in her life and requested a break in study activities (i.e., a major event) when other major changes occurred (e.g., the child going to preschool). Similarly, when the father left on or returned from a business trip, the mother requested a break so that the child could adjust to the father’s absence and the family could reconnect when the father returned. When the mother requested these breaks as well, I accepted that these were a part of the family’s life, honoured the family’s request for a pause or break in the study, and rescheduled support and research activities when the family was ready to do so.

In addition to delays, which served to slow down the support and research process, obstacles that functioned to interfere with the process also were encountered. Across the course of the intervention phase, three obstacles were encountered: (a) the father’s business travel; (b) the introduction of non-evidence based practices, including a weighted blanket and a diet called the Gut and Psychology Syndrome (GAPS) diet (Campbell-McBride, 2010); and (c) the mother hesitating to progress through the final fading steps in leaving the child’s bedroom and the child falling asleep alone.

When an obstacle to child and family progress arose during the intervention phase, I asked to meet with the mother or both parents and engaged in a collaborative, problem solving discussion. On two occasions, my thesis advisor joined the meeting and participated in the discussion. During the discussion, the obstacle to child progress was described to the parent(s) and the parent(s) was invited to participate in a problem solving
discussion aimed at finding a solution that was acceptable to the family and allowed the child and family to continue to make progress toward their vision of a successful bedtime routine. Each of the obstacles and the steps taken to overcome them are described below.

2.13.1.1 Father’s Business Travel

Business travel, for the purpose of this study was defined as working away from home for extended periods of time (i.e., 2-3 weeks). Initially, it was believed that the father’s business trip schedule would be temporary. However, it was later confirmed that it would be an ongoing occurrence. During the course of the intervention, it became increasingly apparent that the child’s behaviour during the bedtime routine was being affected by the father’s business trips. Clinical observations, combined with parent report, indicated that the father’s business trips were associated with the child becoming agitated and exhibiting anxiety when the father left for an extended business trip. The father’s departures and returns were associated with the boy having difficulties going to bed and sleeping through the night.

To address this obstacle, two meetings were scheduled with the family. During the first meeting, Dr. Joseph Lucyshyn and I met with both the mother and the father. First, we discussed the father’s business trip schedule. The parents informed us that, although the father’s business travel was initially temporary, the father now would be travelling for work frequently over the next year. Given this and the association between the father’s business travels and child problem behaviour, the parents agreed that additional behaviour supports would be necessary. We then used a competing behaviour pathways framework to analyze the conditions associated with child problem behaviour related to the father’s extended business trips. From this analysis, we developed a
summary statement of the problem which included the function of child problem
behaviour, the setting events that set the stage for the problem behavior and the
antecedent stimuli that triggered the problem behaviour. The results of this analysis are
presented in Table 2.10a (see Table 2.10a). Then, based on the competing pathways
diagram, a behaviour support plan was collaboratively developed with the child’s parents
that aimed to minimize or neutralize the effect of the father’s business travel on the
child’s sleep behaviour, and to strengthen the child’s sleep behaviour during the father’s
departures, absences and returns. The behaviour support plan for the father’s business
travel is presented in Table 2.10b (see Table 2.10b).

A second meeting was scheduled with the mother to review the finalized plan.
During the meeting, the mother reported that the family had already begun implementing
several of the strategies outlined in the plan and that the child’s behaviour had improved
considerably. Based on this, strategies from the PBS plan for the father’s business travel
were abridged and consolidated into the bedtime implementation checklist as a setting
event strategy with several components.

2.13.2 Introduction of Non-Evidence Based Practices

Non-evidence based practices are defined as those practices that are not
empirically-based. Non-evidence based practices that were introduced by the family
included: (a) a weighted blanket; and (b) the GAPS diet. These obstacles were associated
with increases in problem behaviour.
Table 2.10a  Competing behaviour pathways diagram: Problem behaviour associated with the father’s frequent business travels

<table>
<thead>
<tr>
<th>Setting Event(s)</th>
<th>Antecedent Trigger(s)</th>
<th>Problem Behaviour</th>
<th>Maintaining Consequence</th>
<th>Maintaining Consequence</th>
<th>Alternative Replacement Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dad goes away (sometimes for a few weeks) -Separation anxiety</td>
<td>Mom tells N he can’t see dad Mom places a demand/request to transition to less preferred activity</td>
<td>Crying/asking for dad Demands that Mom stays with him N wakes up at night (2-3 times)</td>
<td>Contact Dad by phone N gets to do a preferred activity with Mom Mom lies on N’s couch, gives N a glass of milk, and/or N sometimes sleeps with Mom</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N requests to talk to Dad (e.g., “Let’s phone Dad”)</td>
<td>N feels comfortable and safe and remains cooperative N sleeps regularly</td>
<td>Descriptive verbal praise; reward in the morning for sleeping through the night</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2.10b Positive Behaviour Support Plan: Problem behaviour associated with the father’s frequent business travels

<table>
<thead>
<tr>
<th>Setting Event Strategies</th>
<th>Preventative Strategies</th>
<th>Teaching Strategies</th>
<th>Consequence Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease N’s anxiety and increase N’s understanding about Dad leaving by:</td>
<td>In the morning, review the calendar stating when Dad is away and when he’ll be back and cross out how many sleeps until Dad returns</td>
<td>Teach N to self-regulate/self soothe (e.g., “Dad’s gone, it’s ok”) using direct instruction (i.e., modeling the words, sentences, phrases about Dad returning, love and his own sense of calmness and giving him praise for using these words)</td>
<td>Throughout the day notice and give N descriptive praise when he is calm and Dad is away</td>
</tr>
<tr>
<td>Setting up a calendar with Dad 2-3 days before leaving that visually depicts (a) when he is going away; (b) number of sleeps; and (c) when he is going to be back</td>
<td>Remind N of the gift Dad will be bringing back when he returns</td>
<td>Prompt N to ask to call Dad</td>
<td>When N sleeps through the night, provide contingent praise and a reward for doing it without Dad and staying calm (e.g., “Dad is away and you were calm and stayed in your bed all night!”)</td>
</tr>
<tr>
<td>Each time Dad comes back, have him bring back a small gift/present for N so that he has something to look forward to upon his return</td>
<td>Let N know when he will be receiving a phone call, a video phone call, or a picture from Dad</td>
<td></td>
<td>When N asks to call Dad, negotiate and use a safety signal (e.g., “We can call Dad, but he may not be there, and if he isn’t, what can we do?”)</td>
</tr>
<tr>
<td>Read N a social story about Dad begin away focusing on reasons why Dad goes away, that Dad always comes back, and that love protects you (like an umbrella) and as long as you know this you can be calm and cooperate</td>
<td>When N talks about Dad or shows some mild anxiety, give N information and reassurance</td>
<td></td>
<td>When N asks nicely for reassurance, immediately provide reassurance and information (e.g., remind N when he will get to talk to Dad, suggest writing in his notebook about what he’s going to talk to Dad about)</td>
</tr>
<tr>
<td>Set up regularly scheduled times to contact Dad</td>
<td>Make a book of his day together so that he can tell Dad when he talks to him</td>
<td></td>
<td>If minor problem behaviours occur, tell N you can’t talk about this, take a break, and minimize your attention/interaction with N</td>
</tr>
<tr>
<td></td>
<td>Use a pre-correction strategy to remind N to politely ask to call Dad</td>
<td></td>
<td>If major problem behaviours occur, remove attention (for 1-2 minutes), then redirect and go back to proactive strategies</td>
</tr>
</tbody>
</table>
2.13.2.1 Weighted Blanket

A weighted blanket is a custom-made blanket that has been filled with a specific material that gives the blanket added weight (Olson & Moulton, 2004). Although it is believed that weighted blankets can help children with autism to cope with a wide range of problems, including hyperactivity and sleeplessness, the therapeutic value of weighted blankets has not been proven scientifically. Empirical support is scarce and often plagued by weak experimental designs and poor fidelity (Parham et al. 2007). During the third month of the intervention phase, the child’s Occupational Therapist recommended that the mother use a weighted blanket when putting him to bed. Subsequently, the mother began to use a weighted blanket during the bedtime routine. Following this, the mother reported an increase in the child’s sleep disturbances when going to sleep and during the night. To address this problem, the mother agreed to meet with me to engage in a problem solving discussion. First, the mother and I discussed the recent increase in sleep disturbances and the association between these disturbances and the introduction of the weighted blanket. In order to examine if the weighted blanket was having an effect, either negative or positive on the child’s sleep, the mother was asked to review the sleep diary. The sleep diary revealed a sudden increase in latency to falling asleep and frequency of night wakings beginning the night the weighted blanket was introduced. Given this evidence, the mother agreed to suspend the use of the weighted blanket for a few nights to see if there would be any difference in the child’s sleep. Following the removal of the weighted blanket, the child’s sleep quickly normalized (i.e., falling asleep within 20 minutes, less than four night wakings per night). The mother subsequently discontinued the use of the weighted blanket. In this case, an amendment to the bedtime PBS plan was not necessary.
2.13.2.2 Gut and Psychology Syndrome (GAPS) Diet

The GAPS (Gut and Psychology Syndrome) diet is centred on the theory that children with autism have a deficiency in their digestive system (Campbell-McBride, 2010). The theory submits that children with autism have dysfunctional gut flora and thus are prone to collecting particular toxins. These toxins create an “abnormal microbial mass” in the child’s digestive tract, which in turn contributes to the symptoms of autism (Campbell-McBride, 2010).

Although there is no empirical evidence to support this theory or the efficacy of the GAPS diet, the diet has found a following among some families of children with autism and among professionals that provide adjunct services to these families (e.g., nutritionists). I was informed by the mother that she had attended a workshop by the founder of the method, Dr. Campbell-McBride, and was placing her child on the GAPS diet. The diet has a number of phases, and involves the removal of processed foods, grains of any sort, starchy /root vegetables, beans, dairy, soy, sweeteners (including natural sweeteners), and fruit juice. In the early stages, the child is only allowed to consume broth, and permitted foods are gradually introduced.

The introduction of the GAPS diet proved to be a significant obstacle to the child’s progress in the bedtime routine. This setting event was associated with an increase in the child’s problem behaviour during the day, an increase in bedtime disturbances during the going to bed and falling asleep steps in the bedtime routine, and an increase in the number of nights that co-sleeping occurred. From a functional analytic perspective, the introduction of the diet added punishing events into the child’s life on a daily basis: The removal of all preferred foods, and the addition of many non-preferred foods and beverages.
Shortly after introducing the GAPS diet, due to the intensity of the experience for the mother and child, the mother requested a break from the study until the more intense phase of the diet was completed. The break occurred in December 2010 and the first half of January. In mid-January, the mother consented to participate in a meeting to discuss the GAPS diet and the child’s progress in the bedtime routine. Dr. Joseph Lucyshyn and I participated in the discussion with the mother. During the discussion, we informed the mother of the non-evidence based nature of the diet and our hypothesis about the effect of the diet on her child’s sleep behaviour. We also sought to normalize the mother’s decision to pursue this diet by informing her of the fact that many families of children with autism choose to implement non-evidence based interventions with their children with autism. We informed the mother of a recent study (Green et al., 2006), for example, that showed that families of children with autism on average, choose to implement 7 interventions concurrently, a fair proportion of which were non-evidence based interventions. Following this information, the mother reiterated her desire to continue the GAPS diet but also informed us that the child had completed the most severe stages of the diet and at the current stage, a wider range of new foods were being introduced. Given this, the mother agreed to a compromise that accommodated both the GAPS diet and the need to preserve the child’s quality of life at home as it related to the food he was allowed to eat. The mother agreed to the following accommodations: (a) highly preferred foods that were compatible with the GAPS diet would be available every day (e.g., zucchini pancakes with diluted honey); (b) positive events, including parental praise and preferred activities, would be increased during the day while the GAPS diet was in place; and (c) demands to do difficult or non-preferred tasks would be decreased throughout the
day while the GAPS diet was in place. The mother later reported that she implemented these strategies immediately following the meeting, and within days she began to see an improvement in the child’s behaviour during the day and during the bedtime routine.

2.13.2.3 Mother Hesitating to Progress through the Final Fading Steps

At two points during the intervention, the mother hesitated to progress through the steps in the fading hierarchy. The mother hesitated when it was time for her to move from step 3 (i.e. the mother sitting inside the child’s room at the door with the door closed) to step 4 (i.e., the mother sitting outside the child’s door with her back pushed up against a curtain). The mother also hesitated when it was time for her to move from step 5 (i.e., the mother sitting outside the child’s door with the curtain closed) to step 6 (i.e., the mother conducting check-ins).

In each of these instances, I noticed that the mother began cancelling training sessions and that there was a delay in her returning my phone calls. I had previously indicated that, although we were going to approach each step as errorlessly as possible, she may see an increase in the child’s problem behaviour when moving to the next step in the fading hierarchy. This was particularly emphasized when moving from step 5 to step 6, the final step in the fading process. I also let the mother know that it would likely involve more effort on her part, as she might initially need to conduct frequent check-ins. Thus, when the mother began to cancel sessions and delay returning my phone calls, I supposed that the mother was apprehensive about moving forward and progressing to the next step in the fading process, as she anticipated that potential challenges might arise. I also supposed that the mother had gotten to a point in the fading process where she felt comfortable, as the child was exhibiting low levels of problem behaviour and was falling
asleep relatively quickly (i.e., within 20 minutes). I also believed that the mother had begun to associate me with demands (e.g., conducting training and observation sessions in the family’s home 1-2 times per week, moving to the next step in the fading process, requesting the mother collect data in the sleep diary).

In response to the mother’s hesitancy, I refrained from pressuring the mother to schedule training sessions; rather, we agreed that I would contact her once a week to check in and to see if she was ready to reinitiate the support process. In addition, following the Christmas holiday, in early January, I visited the mother informally just to check-in and reconnect.

During the meeting that was held to discuss the GAPS diet, we also discussed the mother’s hesitancy in moving to the next step in the fading process of the bedtime routine. Prior to this discussion, we first sought to find out if the mother wished to continue or terminate her participation in the study. The mother was reminded that she had every right to terminate participation in the study and that we would be supportive of whatever decision she made. The mother responded unequivocally that she wished to continue participation. We then asked permission to discuss her hesitancy to progress to the next fading step and the effect that this may have had on her son sleeping through the night. Following the mother’s assent, we used a visual presentation to communicate the relationship between the mother sitting at the door when the child fell asleep and his inability to go back to sleep when he woke up in the middle of the night. The visual illustrated the following point: Because the child had learned to fall asleep when the mother was sitting by the door, when the child woke up at night, he was not able to fall back asleep because his mother was no longer sitting by the door. It was further explained
that the way to teach him to fall asleep independently after waking up in the middle of the night was for her to fade her presence out completely by moving to the final step in the fading hierarchy. In response, the mother expressed her understanding and acceptance. Following this meeting, the mother informed me that she had regained her motivation, and was ready to progress to the final fading step. During a subsequent meeting with the mother, she requested details on how to implement the check-in phase (i.e., the sixth and final fading step). I explained the process to her and mapped out how she would fade her presence. After explaining the process, the mother indicated that she would like to attempt the check-in phase independently, without a formal training session. Within a week, the mother reported that she had successfully faded to a point where she was performing brief check-ins with the child every 10 minutes (no time at the door), and that he was usually asleep by the second check-in. Subsequent observation probe sessions confirmed this verbal report.

2.14 Research and Intervention Procedures

The sequence of the research procedures went as follows: (a) preliminary screening assessment; (b) baseline; and (c) intervention (including responses to delays and obstacles).

2.15 Preliminary Screening Assessment

In order to identify a child and family that met the criterion for study participation, a series of preliminary screening activities was conducted. Preliminary screening activities included: (a) conducting a prescreening interview; (b) administering The Albany Sleep Problems Scale (ASPS); and (c) completing a family routine assessment with the parents. The assessment procedures are described below.
The Albany Sleep Problems Scale (ASPS) (Durand, 1998), a 46-item questionnaire designed to assess the type and severity of sleep problems was administered to determine whether or not the child’s sleep problems warranted the need for an intensive intervention for such problems (see Appendix N). In addition to the questionnaire, a semi-structured interview, approximately 60 minutes in length, was conducted in which the parents answered open-ended questions regarding the child’s sleep history, sleep habits, current sleep problems and current and previous techniques employed by the parents. The results of the ASPS confirmed that the child met the study’s criteria of having bedtime disturbances and co-sleeping problems. The results of the ASPS also indicated the child did not have any medical conditions that may be related to his sleep problems.

In a subsequent meeting, the parents were then asked to describe their vision of a successful bedtime routine (i.e., the envisioned bedtime routine). Information was gathered in regards to the time and place of the routine, the people who would be involved, the resources needed to make the routine successful, the steps and sequence of the routine, and the goals and values that would be reflected in the routine (Lucyshyn et al., 2002). The parents envisioned routine was summarized and then presented to the parents for confirmation. Following this meeting, two pilot observations in the bedtime routine were conducted to verify the occurrence and function of the problem sleep behaviours.

2.16 Baseline

Baseline data collection was conducted in the family’s home. Probe observation sessions of the child going to bed and falling asleep were conducted during baseline. During observation probes, direct observation data was collected on the dependent variables as described above (i.e., percentage of intervals of bedtime disturbances, latency
to termination or successful completion of the bedtime routine, parent implementation fidelity of PBS plan). Before conducting a probe observation, the mother was asked to read the summary of the envisioned bedtime routine. The mother was then asked to implement the envisioned routine with her child. The routine was then recorded until a criterion level of problem behaviour was reached, or until the child fell asleep. The morning after a probe observation, I called the mother and asked until what time the child slept (e.g., 6:00 am or 7:00 am). Unlike the intervention phase, during baseline, the mother did not collect additional probe observations of the falling asleep portion of the routine. To minimize physical and psychological risks to the child and the parents, the mother was not asked to attempt the envisioned bedtime routine independently without support.

Also unlike the intervention phase, during baseline, the mother did not gather, in a semi-structured diary, data on the frequency of night wakings and the duration of night wakings. These data were not collected because the mother was co-sleeping with the child in the parent’s bedroom during baseline. Thus, the sleeping through the night data for baseline would not be comparable to the sleeping through the night data during intervention. In addition, to request that the mother attempt to keep the child in his own bed and throughout the night without support would have placed the child and parent at significant psychological and physical risk.

Throughout baseline, the mother was not given any instructions on how to address the child’s sleep problem. Once a stable baseline was established, the intervention phase of the study was introduced.
2.17 Intervention

During the intervention phase, the components of the PBS approach were implemented, including: (a) comprehensive assessment; (b) PBS plan development; (c) implementation plan development; and (d) implementation support. As each of these phases were described in more detail in the “Independent Variable” section above, a brief description of the steps in the intervention process are provided below.

2.17.1 Comprehensive Assessment

A FAI (O’Neill et al., 1997) was completed with the family in order to determine the function of the child’s behaviour. Next, a family ecology assessment (Lucyshyn et al., 2002) was completed to determine the family’s goals, strengths, resources and social supports and sources of stress.

2.17.2 PBS Plan Development

In collaboration with the family, a PBS plan was developed for the bedtime routine. The results of the FAI and the family ecology assessment were used to develop summary statements and competing behaviour pathways diagrams for the bedtime routine. The PBS plan was designed to include technically sound and contextually appropriate strategies to address problem sleep behaviours.

2.17.3 Implementation Plan Development

Immediately following the development of the PBS plan for the bedtime routine, an implementation plan, as described above, was developed.

2.17.4 Implementation Support during Intervention

Implementation support began once the PBS plan and the implementation plan were developed. The family was given a written behaviour support plan and an implementation checklist to support the family’s implementation of the PBS plan.
Training and support activities, as described above, occurred approximately one to two times a week, depending on the family’s availability, for one to two hours per session.
3 Chapter: Results

3.1 Results

To evaluate the impact of the family-centred PBS approach, the study included seven dependent variables directly related to sleep: (a) percentage of intervals of bedtime disturbances; (b) latency in minutes to termination or successful termination of the routine; (c) percentage of steps successfully completed in the bedtime routine; (d) average latency to falling asleep per week; (e) average number of night wakings per week; (f) average duration of night wakings per week; and (g) number of nights in which co-sleeping occurred per week. Additionally, the study included four dependent variables, not directly related to sleep: (a) parent implementation fidelity of the PBS plan; (b) average parent rating of the social validity of the support; (c) average parent index of the support plan’s goodness-of-fit; and (d) average rating of the family’s quality of life. These results are summarized below.

3.1.1 Percentage of Intervals of Bedtime Disturbances

Figure 3.1 shows the percentage of intervals of bedtime disturbances during full probe observation sessions (i.e., going to bed and falling asleep steps) and partial probe observation sessions (i.e., falling asleep steps). Overall, the data revealed marked improvement in the bedtime routine.

During baseline, the percentage of bedtime disturbances averaged 69.6% across 3 full probe observation sessions (range, 60.6% – 80.0%). The data indicated an increasing trend. During intervention, bedtime disturbances across 9 full probe observations dramatically decreased to an average of 5.0% of intervals (range, 3.0% – 10.4%). During intervention, percentage of bedtime disturbances across 10 partial probe observation sessions indicated stable, low rates of problem behaviour with an average of 4.4% of
Figure 3.1 Percentage of Intervals of Bedtime Disturbances, Percentage of Steps Completed and Latency in Minutes to Successful Completion or Termination of the Routine. In the intervention phase the numbers 1, 2, 3, 4, 5 and 6 between data paths indicate a gradual fading strategy during the bedtime routine: 1=mother beside the child’s bed; 2=the mother on the couch in the child’s room; 3=the mother sitting inside the child’s room at the door with the door closed; 4=the mother sitting outside the child’s door with her back pushed up against a curtain; 5=the mother sitting outside the child’s bedroom with the curtain closed; and 6=the mother leaving the child’s bedroom and doing brief check-ins. The asterisk (*) and break mark (//) across the intervention phase between September 2010 and February 2011 represents a break in the support process due to family vacations, the father’s business travel, illness, Christmas holidays and the introduction of the GAPS diet.
intervals (range, 0.0% – 7.4%).

Taken as a whole, percentage of bedtime disturbances across 9 full probe observation sessions and 10 partial probe observation sessions indicated stable, low levels of problem behaviour with a combined average of 4.7% of intervals (range, 0.0% – 10.4%).

3.1.2 Latency in Minutes to Termination or Successful Completion of the Routine

Figure 3.1 shows the latency in minutes to termination due to problem behavior or to successful completion of the bedtime routine during full probe observation sessions (i.e., going to bed and falling asleep steps) and partial probe observation sessions (i.e., falling asleep steps).

During baseline, across the 3 full probe observation sessions the child spent an average of 5 minutes, 9 seconds in the bedtime routine (range, 5:07 – 5:12) before the criteria for termination of the routine was met. All 3 baseline observations required termination of the routine because 5 instances of tolerated problem behavior occurred (i.e., 5 instances of elopement or 5 instances of defiance/verbal protest). During intervention, latency to successful completion across full probe observation sessions increased to an average of 58 minutes, 48 seconds (range, 41:10 – 1:16:00). During intervention, latency to successful completion across partial probe observation sessions evidenced an average of 12 minutes, 20 second (range, 7:00 – 18:00).

3.1.3 Percentage of Steps Successfully Completed in Bedtime Routine

The percentage of steps successfully completed during the bedtime routine across full probe observation sessions (i.e., going to bed and falling asleep steps) and partial probe observation sessions (i.e., falling asleep steps) is shown in Figure 3.1.

During baseline, across the 3 full probe observation sessions the child completed an average of 28.1% of 13 steps in the bedtime routine (range, 23% – 30.7%). During
intervention, the number of steps successfully completed across full probe observation session increased to 94.8% of 13 steps (range, 92.3% – 100%). During intervention, the percentage of steps successfully completed across partial probe observation session increased to 94.9% of 6 steps (range, 83.3% – 100%).

3.1.4 Average Latency to Falling Asleep per Week

Figure 3.2 displays the average latency to falling asleep per week. Data with respect to latency in minutes to falling asleep were recorded by the mother using a semi-structured sleep diary (see Appendix F). I then used these data to calculate the average latency to falling asleep for each week. During baseline, data with respect to latency to falling asleep were not collected because the mother was co-sleeping with the child. Data with respect to latency to falling asleep were not collected during week 22 because the mother was co-sleeping with the child during a family vacation to Oregon. Additionally, during the check-in phase of the fading process (i.e., the mother leaving and briefly checking in at 5-15 minute intervals), latency to falling data was not collected because the mother was no longer able to accurately determine when the child fell asleep. During intervention, latency to falling asleep averaged 14.4 minutes across 44 weeks (average weekly range, 6.0 – 32.9, daily range, 2 – 88). Across the 11 weeks, a decreasing trend in average latency through week 15 was followed by high variability through week 40. Subsequently, a decreasing trend was evidenced from week 44 to 46. Increases in these data were associated with: (a) the father’s return from business travel; (b) child illness; (c) the child napping during the day; (d) “exciting events” (e.g., Christmas, child’s birthday); and (e) the introduction of the GAPS diet.
Figure 3.2  Average Latency to Falling Asleep per Week. The numbers above the data points on the graph represent events as follows: (1) father’s return from a business trip; (2) family vacation; (3) daylight savings change; (4) child illness; (5) child illness and napping during the day; (6) Christmas holiday, the child’s birthday celebration, child illness and the introduction of GAPS diet; (7) child illness, GAPS diet and the child’s return to school; (8) napping during the day; and (9) mother no longer able to accurately collect data on latency to falling asleep due to the 6th and final fading step (i.e., check-ins).

3.1.5  Average Number of Night Wakings per Week

Figure 3.3 displays the average number of night wakings per week. Data with respect to the number of night wakings was recorded by the mother using a semi-structured sleep diary (see Appendix F). I then used these data to calculate the average number of night wakings for each week. During baseline, data with respect to the night wakings was not collected because the mother was co-sleeping with the child. Data with respect to number of night wakings was not collected during week 22 because the mother was co-sleeping with the
Figure 3.3 Average Number of Night Wakings per Week. The numbers above the data points on the graph represent events as follows: (1) introduction of weighted blanket; (2) father’s return from a business trip; (3) father departing for a business trip; (4) child illness; and (5) family vacation.

A child during family vacation to Oregon. During intervention, the number of night wakings averaged 0.7 across 46 weeks (average weekly range, 0 – 3.3, daily range, 0 – 5). These data also evidenced a decreasing trend across the 44 weeks. Increases in these data were associated with: (a) the introduction of a weighted blanket; (b) the father’s departing or returning from business travel; and (b) child illness.

3.1.6 Average Duration of Night Wakings per Week

Figure 3.4 displays the average duration of night wakings per week. Data with respect to the duration of night wakings was recorded by the mother using a semi-structured sleep diary (see Appendix F). I then used these data to calculate the average duration of night...
Figure 3.4 Average Duration of Night Wakings per Week. The numbers above the data points on the graph represent events as follows: (1) introduction of weighted blanket; (2) father’s return from a business trip; (3) father departing for a business trip; (4); family vacation and (5) child illness.

Wakings for each week. During baseline, data with respect to duration of night wakings was not collected because the mother was co-sleeping with the child. Data with respect to duration of night wakings was not collected during week 22 because the mother was co-sleeping with the child during a family vacation to Oregon. During intervention, duration of night wakings averaged 7.6 minutes across 46 weeks (average weekly range, 1.0 – 28.3, daily range, 1.0 – 88.0). These data also evidenced a decreasing trend over time, with notable exceptions during weeks 9, 10, and 43. These momentary increases were associated with: (a) the introduction of a weighted blanket; (b) the father’s departing or returning from business travel; and (b) child illness.
3.1.7 Number of Nights in which Co-sleeping Occurred per Week

Figure 3.5 displays the number of nights in which co-sleeping occurred per week. Data with respect to co-sleeping was recorded by the mother using a semi-structured sleep diary (see Appendix F). I then used these data to calculate the number of nights co-sleeping occurred each week. During baseline, the mother co-slept with the child every night (i.e., 7 days a week or 100%). During intervention, the number of nights of co-sleeping that occurred decreased precipitously to an overall average of 0.7 times per week across 47 weeks (range, 0.0 – 7.0). Increases in these data were associated with: (a) family vacations; and (b) the GAPS diet.

Figure 3.5 Number of Nights in which Co-sleeping Occurred per Week. The numbers above the data points on the graph represent events as follows: (1) family vacation; (2) family vacation; (3) family vacation; (4) family vacation; (5) GAPS diet; and (6) GAPS diet.
3.1.8 Parent Implementation Fidelity of the PBS Plan

Parent implementation fidelity data were gathered across 26.3% of probe observation sessions (i.e., across 3 full and 2 partial probe observation sessions). During intervention, the parent’s average percentage of intervals of accurate use of strategies was 86.6% (range, 73.9 – 92.8%).

3.1.9 Average Parent Rating of the Social Validity of the Support

A social validity questionnaire was used to assess the acceptability of intervention goals, procedures and outcomes (Lucyshyn et al., 1997). The average social validity rating was 4.7 out of 5 (range, 4.7 – 4.8). Overall, the child’s mother perceived the plan goals, procedures, and outcomes as acceptable. Table 3.6 presents the comments made by the mother during intervention regarding the acceptability and importance of the family-centred PBS approach.

3.1.10 Average Parent Index of the Support Plan’s Goodness-of-Fit

A “goodness-of-fit” assessment in the form of a questionnaire was used to evaluate whether the support plan was a good fit with the ecology of the family (Albin et al., 1996). The average goodness-of-fit index was 4.7 out of 5 (range, 4.5 – 5). Overall, the child’s mother perceived that the support plan fit well with the family’s ecology. Table 3.7 presents the comments made by the mother during intervention regarding the acceptability and importance of the family-centred PBS approach.

3.1.11 Average Rating of the Family’s Quality of Life

The family’s perception of their overall quality of life was measured by administering The Beach Centre Family Quality of Life Survey (Beach Centre, 2001). During baseline, the mother’s overall average rating of the family’s quality of life rating was 3.9 out of 5. Quality of life slightly improved following the implementation of the PBS approach. During
Table 3.6 Mother’s Social Validity Comments during Intervention Organized by Goals, Procedures and Outcomes

<table>
<thead>
<tr>
<th>Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appropriateness of the goals:</strong> The goal was always to get N to go to bed without fuss and stay in his bed all night. This is appropriate for a child of his age.</td>
</tr>
<tr>
<td><strong>Consistency of the plan with family goals and values:</strong> Sleep is very important to us—and it is important for our son to also get a good night’s sleep.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of difficulty of the strategies:</strong> Not at all. We felt no hesitation at saying if something didn’t work and were given alternate strategies to try.</td>
</tr>
<tr>
<td><strong>Effectiveness of the strategies:</strong> Absolutely! And not just for sleeping but for his behaviour in general.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of benefit to child:</strong> He is sleeping longer and all night, instead of waking up every couple of hours.</td>
</tr>
</tbody>
</table>

**Level of benefit to family:**

Yes. My husband and I have more time for each other, and we are both getting better sleep and can therefore function better.

We have a happier, more rested child which makes us happy. We have new strategies that work not just for sleeping but for improving other behaviours also so we have less stress in dealing with our son and therefore can enjoy each other more.

**Unanticipated problems:** None that were not expected.

**Support during training activities:** Yes. Rachel always had handouts for us and went over the strategies/routines beforehand until it became second nature. Feedback was always provided in a positive manner.

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Table 3.7 Mother’s Goodness-of-Fit Comments during Intervention

This whole year of working with Rachel and Joe has been amazing. There is no way we could have gotten our son to sleep in his own bed without their support and encouragement. At the worst times (i.e. getting up every two hours to put our son back to his room and sitting in a chair while he went back to sleep), I didn’t really believe it would work, but they promised that it would, based on past experience. That gave me the strength to continue. Every time there was a new challenging situation, they were there to support us through it and give us new strategies (or remind us of old ones we had forgotten about!) to redirect/improve behaviour.
intervention, the mother’s overall average rating of the family’s quality of life increased to 4.1 out of 5. These data indicate that the child’s mother perceived the family’s overall quality of life improved for the family following the implementation of the PBS approach.

3.1.12 Debriefing Questionnaire

A brief, debriefing questionnaire comprised of 9 open-ended questions was used to assess the mother’s experience and perspective regarding: (a) her expectations related to the study and its goals; (b) delays and obstacles encountered; (c) pace of the study; and (d) the interventionist’s response to the mother’s introduction of additional interventions. In addition, a final set of questions asked the mother to share any advice she would give to families and feedback she would offer to interventionists in relation to participating in a family-centred PBS intervention focused on sleep problems. The mother completed the questionnaire at the end of the intervention phase. The mother’s responses to the questions are summarized in Table 3.8 below.
Table 3.8  Debriefing Questionnaire

1. Coming in to the study, what expectations did you have in terms of support, and also outcomes for your child?
My expectations were not specific, more general - to give me the tools/strategies to get my child to go to sleep in his own bed by himself and for us all to enjoy the process. I was, like every other parent with a child with a disability (or even a "typical child"), looking for a miracle fix or cure that would instantaneously solve the issues. But this is not reality.

2. How did your experience of being in this study relate to these expectations?
There were definitely ups and downs - usually related to how well the sleep was going. It was sometimes difficult to just "take your word that it will work" as the whole process seemed to go quite slowly. But I have gained a lot of insight from the experience and can see the tools and strategies spilling into other aspects of our lives.

3. During the course of the study, there were a number of times when you asked us to pause, or take a break. Can you describe some of these experiences?
There were periods when the sleep was going pretty well for N and I was actually getting a good night sleep too. I knew that when we moved to the next stage, we may see some regression and I first needed to enjoy and catch up on my sleep again, and also mentally prepare myself for the possibility that my sleep would be interrupted again. I also added a couple of new activities for N so I was doing quite a lot of running around and found it challenging to be prepared for an evening session as well.

4. What was your experience with how we responded to your requests to take a break?
You were very accommodating.

5. What might have been your experience if we said that we had to keep up a schedule, and pushed to continue support during these times?
I am sure I would have been cranky about it but would have gotten over it - usually if I am given a good reason for something, I am pretty accommodating. I just need to hear the reasoning and the scientific evidence to back it up.

6. During the course of the study, you decided to add an additional intervention to your child’s routine. What was your experience with our response to this?
Again, very accommodating. When I previously hired a sleep consultant (N was about 1/1/2 years old), it was pretty much a "set" schedule/routine. When I found that this didn't work, I was told I was doing something wrong or wasn't following her routine. That was very frustrating as she ended up being absolutely no help. So having the flexibility to add/change/adapt to my child made the process work.

7. In general, what was your experience of being involved in this study?
Overall it has been an awesome experience - and I have learned so much more than just how to put N to bed - the strategies and techniques can be used in a variety of situations.

8. What advice would you give to other families going into this type of intervention?
It is definitely doable, but it is not an overnight fix and that it is important to have support - for example, in the beginning, I would have a nap while N had his therapy sessions. I could call on my parents and they would help on difficult days.

9. If you were to provide any feedback that might help us when working with future families, what advice would you give?
To follow the steps, even if you are not sure they will work because they do eventually. Don't give up, even when you feel the very worst. Make sure to have good support, especially at the very beginning, and plan for naps!
4 Chapter: Discussion

4.1 Summary of Results

The purpose of the study was to investigate the effectiveness and acceptability of a family-centred, PBS approach for decreasing sleep-related problem behaviour during a bedtime routine for a 4-year-old child with autism. The results, comprised of multiple outcome measures, offer evidence of a strong association between a parent implementation of a multicomponent PBS plan and improvements in sleep-related behaviour within a valued bedtime routine.

Results from probe observation data showed that following parent implementation of the multicomponent PBS plan, there was an immediate and dramatic improvement in: (a) the percentage of intervals of bedtime disturbances; (b) latency to termination or successful completion of the bedtime routine; and (c) steps successfully completed in the bedtime routine. These improvements in child behaviour were maintained for 11 months over the course of intervention.

In addition, results showed that during plan implementation, parent report data indicated age-appropriate levels of: (a) latency to falling asleep (i.e., approximately 20 minutes or less); and (b) number of night wakings (i.e., approximately 4 or less). During baseline, the mother co-slept with the child every night. During intervention, results indicated low to zero levels of co-sleeping. Nights in which co-sleeping occurred were related primarily to: (a) the introduction of significant dietary changes (i.e., the GAPS diet); and (b) pre-planned co-sleeping when the family was on vacation. Results also indicated low levels of duration of night wakings with a few exceptions. Nights in which the duration of night wakings was significantly higher than the average were related primarily to: (a) child illness; and (b) the introduction of a weighted blanket.
Social validity and goodness-of-fit ratings indicated that the mother viewed the PBS plan as important and acceptable in regard to goals, procedures and outcomes, and that she viewed the PBS plan as possessing a good contextual fit with the family’s goals, expectations and resources. Quality of life ratings indicated modest gains. However, the family indicated a relatively high quality of life from the outset.

In addition, high parent implementation fidelity data suggest that the family support process was associated with the mother accurately using the behaviour support plan strategies to effectively support and teach her son to participate cooperatively in the bedtime routine; (b) the mother supporting her son to sleep through the night in his own bed, fall asleep without the mother’s presence, sleep through the night, and stay in bed until 6:30am.

In addition to these results, the mother’s responses to the debriefing questionnaire provided additional insight into effectiveness and acceptability of the intervention. The mother reported gaining the ability to generalize the skills learned in the bedtime routine to other settings. The mother indicated that the overall pace of the study was slow at times, but that the pauses and breaks were necessary in order for her to catch up on sleep and mentally prepare herself for the next stage of the intervention. In addition, the mother indicated that the flexibility of the interventionist and the willingness to make adaptations and accommodations to the family contributed to the effectiveness and acceptability of the intervention. The mother also indicated that at times, she found aspects of the intervention challenging. During these times, she highlighted the importance of using natural resources and social supports to help her through these difficult stages of the intervention (e.g., respite from grandparents, taking naps during the day).
4.2 Findings in Relation to the Literature

This study demonstrated the implementation of a model of support for families of children with autism who exhibit sleep problems that merged best evidence-based practices from the extent literature on behavioural intervention for sleep problems in children with autism with key features of a family-centred PBS approach. In doing so, the study’s results add to and extend the behavioural intervention literature on sleep problems in children with autism in several ways.

First, this study adds to the empirical evidence of the effectiveness of sleep interventions that are based on a functional assessment, that are informed by behavioural theory, and that are implemented by the child’s parents in the home (Christodulu & Durand, 2004; Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Howlin, 1984; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964).

Second, this study confirms the value of developing a collaborative partnership with the child’s family in which sleep intervention components are developed in consultation with family members, and family members play a key role in gathering sleep data (Weiskop et al., 2001; Weiskop et al., 2005).

Third, the study confirms the importance of multicomponent support plans that are based on a functional assessment and that address each function of the child’s sleep behaviours across the four part contingency of setting events, antecedent triggers, problem behaviour, and maintaining consequences (Christodulu & Durand, 2004; Didden et al., 2002; Durand & Christodulu, 2004; Durand et al., 1996; Piazza et al., 1997; Weiskop et al., 2001; Weiskop et al., 2005; Wolf et al., 1964). In this study, the behavioural support plan included six core antecedent and consequence strategies derived from the behavioural sleep literature: (a) elimination of sleep during the day (i.e., removing naps), and starting the child’s bedtime
routine later so that he was tired and thus fell asleep more easily; (b) implementation of a
predicable bedtime routine; (c) use of graduated withdrawal (i.e., the gradual fading
technique); (d) use of graduated extinction (i.e., the check-in phase of the fading technique);
(e) use of positive reinforcement; and (f) removal of reinforcement for problem behaviour. In
addition, the study also included 16 setting event, antecedent, teaching and consequence
strategies that were informed by a competing behaviour pathways diagram and the
evidentiary base of PBS research. These were: (a) providing a large amount of maternal
attention before bed in order to decrease the value of the mother’s attention; (b) using a
visual schedule; (c) using social stories; (d) providing warnings for transitions; (e) providing
the child with more choice and increasing reinforcement for complying with requests if he
was tired or had not eaten properly; (f) embedding playful but not stimulating activities into
transitions; (g) providing choice; (h) using pre-correction statements; (i) using positive
contingency statements; (j) using safety signals; (k) using visual contingency maps; (l)
teaching alternative replacement behaviour; (m) teaching self-help tasks using whole task
instruction; (n) teaching relaxation skills using direct instruction methods; (o) honouring the
child’s appropriate requests (i.e., to have more time; for the mother to come back); and (p)
redirecting the child to use alternative replacement behaviours (i.e., request for more time;
request for the mother to come back), rather than engage in problem behaviour.

This study also extends the literature in a number of ways. First, the study illustrated
the value of conducting a family ecology assessment for the purpose of designing a
contextually appropriate behaviour support plan for a family of a child with autism and sleep
problems. The results of the family ecology assessment were used to build on family
strengths, incorporate natural supports and resources, diminish stressors experienced by
family members, and address the family’s goals for the child and for the family as a whole. For example, the family noted that family time was very important to them. Thus, when the father returned from a business trip and the family requested time to reconnect, I accommodated this request, as it helped the family address some of their goals and also contributed to diminishing family stressors. The family also noted that the child was a quick learner and had an amazing memory. These strengths informed materials that were created for the child, including richer, more informative social stories. Finally, one of the resources available to the family was their strong extended family, including the child’s grandparents. During the intervention phase, the mother utilized the grandparents as a resource that provided respite care for the child and also gave the mother the opportunity to catch up on her sleep.

This study also illustrates the value of using the activity setting as a unit of analysis for defining a bedtime routine that was consistent with the child’s characteristics, congruent with the family’s goals and values, and sustainable with the family’s ecology. For example, because the father was away from the home for 2-3 weeks at a time, the mother’s role as primary implementer of the bedtime routine was a good fit with the family’s ecology. Given the cultural diversity in Canada, using the activity setting as a unit of analysis may help interventionists collaborate with families to design bedtime routines that are well matched to the family’s culture, and opportunities and constraints for their environment.

4.3 Unique Contributions to the Literature

This study also offers two unique contributions to the literature: (a) providing behavioural support to a family within a lifespan perspective; and (b) responding
collaboratively and functionally to a family’s introduction of non-evidence based intervention during a process of PBS.

4.3.1 Providing Behavioural Support to a Family within a Lifespan Perspective

This study contributes to the behavioural sleep literature by illustrating the implementation of a family-centred PBS plan focused on sleep problems in a child with autism within a lifespan perspective. The lifespan perspective (also known as the “life course” perspective) involves a contextual and dynamic approach to the study of change in the lives of individual family members over time, and of families as social units. It focuses on process and change, taking a dynamic, rather than static approach to the study of lives and family (Boss, Doherty, LaRossa, Schumm, & Steinmetz, 2008).

Dunlap and Fox (1999) emphasized that, “family support is a concept that needs to be considered in a broad context because autism is a challenge that affects the entire family in a ubiquitous and longitudinal way.” Lucyshyn et al (2009) have argued that a lifespan perspective can contribute to long term maintenance of behavioural and family outcomes because it allows the interventionist and family to identify and address natural obstacles to maintenance that may arise across an extended period of time across the family’s life. Each obstacle identified and overcome can serve to strengthen the family’s resilience in the face of similar obstacles in the future, and thus advance their ability to maintain treatment outcomes.

Across 11 months of intervention, the family in this study faced several obstacles to the creation of a successful bedtime routine. These included: (a) the father’s business travel; (b) the introduction of non-evidence based practices, including a weighted blanket and the Gut and Psychology Syndrome (GAPS) diet (Campbell-McBride, 2010); and (c) the mother
hesitating to progress through the final fading steps in the bedtime routine. However, within a lifespan perspective, these obstacles became grist of the mill for strengthening the family. For each obstacle, I helped the family understand the way in which the obstacle interfered with the bedtime routine, and engaged in a collaborative dialogue with the family that led to an effective solution. Doing so served to strengthen the family’s understanding of potential obstacles to child progress in the bedtime routine, and further empowered them with additional strategies that advanced the routine’s success. Concurrent with overcoming these obstacles, the parents reported improvements in the child’s behaviour throughout the day. Thus, our work together on these obstacles appeared to strengthen the family’s ability to support their child beyond the limits of the bedtime routine. Walsh (2003) defined resilience as a flexible process in which a family’s strengths are demonstrated at different points during the lifespan of the family and within different circumstances. The family’s progress across the 11 months of the study appeared to illustrate their development of this form of resilience.

4.3.2 Responding Collaboratively and Functionally to a Family Introduction of Non-evidence based Intervention during a Process of PBS

This is the first study in the sleep literature that faced the challenge of addressing non-evidence based interventions with children with autism in the context of implementing a family-centred PBS plan. The importance of this contribution may be seen in the prevalence of families of young children with ASD adopting non-evidence based interventions. Green et al. (2006), in a survey of 552 parents of children with autism, found that parents reported using an average of seven different treatments concurrently, and had used an average of eight treatments in the past. In addition, 10% of the sample reported using 15 or more treatments concurrently. These interventions varied greatly in terms of their degree of empirical support.
More specifically, the results of the study indicated that 27% of parents were implementing special diets (e.g., casein-free, gluten-free), and 43% were using vitamin supplements. The results of the study also indicated that 12% of parents reported currently using a weighted blanket and 25% of parents reported using a weighted blanket in the past.

In this study, the mother introduced two non-evidence based interventions that proved to be problematic during the sleep intervention: a weighted blanket and the GAPS diet. Three factors were associated with being able to overcome these obstacles: (a) developing a strong collaborative partnership between the family and the research team; (b) using acceptance and commitment therapy techniques to accept the obstacle and recommit to the family (Hayes, Follette, & Linehan, 2004); and (c) providing PBS within a lifespan perspective.

This study illustrated how a strong collaborative partnership between the family and the research team can assist in addressing and minimizing the effects associated with parents’ use of problematic non-evidence based interventions. As noted by Dunlap and Fox (1996), a strong collaborative partnership between professionals and families is beneficial for a number of instrumental, social, and emotional reasons. This type of relationship contributes to not only a strong family environment, but also contributes to the success of child behavioural outcomes.

The mother was an invaluable partner throughout the assessment, planning and intervention process. This collaborative partnership proved invaluable when faced with obstacles to the child’s progress during the bedtime routine, such the weighted blanket and GAPS diet. It was through a collaborative dialogue with the parent that we were able to successfully address these obstacles. The collaborative partnership also was essential in helping the mother recognize the relationship between the non-evidence based interventions.
and regressions in child behaviour. Using a functional analytic perspective allowed us to address each obstacle in a reasoned manner, and negotiate a solution that was acceptable and feasible for the mother. Including the mother as an active decision-making partner in finding solutions, appeared to be vital for the continued success of the intervention plan.

In the PBS literature, successful collaborative partnerships between interventionists and families have been identified as relationships that are built on trust, commitment and mutual respect, each of which requires time to develop (Dunlap & Fox, 1996). Elements of successful business partnerships that have been identified in the management literature are very similar to those identified in the PBS literature. Behavioural characteristics of successful business partnerships include: (a) attributes of the partnership, such as commitment and trust (Anderson & Narus, 1990; Salmond & Speckman, 1986); and (b) conflict resolution techniques, which focus on joint problem solving rather than domination or ignoring the problems (Borys & Jemison, 1989). In the management literature, attributes such as commitment and trust imply that both partners acknowledge their willingness to work for the survival of the partnership, and to weather anticipated and unanticipated problems. They also acknowledge that if one party should act opportunistically, the relationship would suffer and both would experience negative consequences (Mohr & Speckman, 1994). Business partnerships that are based on commitment and trust are able to manage greater stress and adapt in response to problems (Zand, 1972). Taken as a whole, these elements of a collaborative partnership appear to have been in place when the unanticipated onset of obstacles occurred during the study.

When obstacles arose, such as the introduction of the weighted blanket or the GAPS diet, both the mother and I displayed a commitment to our partnership, to working through
these problems together and negotiating acceptable solutions from both parties perspectives. In addition, although I was aware that accepting the mother’s introduction of a non-evidence based intervention would likely involve more time and effort in order to resolve, I was committed to the family and the larger goal of supporting the mother to put her child to bed and sleep through the night independently. Also, by using a collaborative approach, I was able to respect and accommodate the mother’s request to continue the GAPS diet with her son, without “dominating” the situation or adhering to an “expert model.” The mother, when completing the debriefing questionnaire, compared the PBS approach with one in the family’s recent past experience that proved to be less accommodating:

When I previously hired a sleep consultant (N was about 1/1/2 years old), it was pretty much a "set" schedule/routine. When I found that this didn't work, I was told I was doing something wrong or wasn't following her routine. That was very frustrating as she ended up being absolutely no help. So having the flexibility to add/change/adapt to my child made the process work.

The collaborative approach also provided a platform for me to address these obstacles from a functional analytic perspective. When an obstacle was identified, a functional analysis using the four part contingency was conducted through my discussions with the mother. Based on this analysis, the mother and I generated logically linked strategies to address the obstacle. This was all done in a collaborative dialogue with the mother. The father’s business travel, for example, was an obstacle that was approached from a functional analytic perspective. In this case, a competing behaviour pathways diagram was used as a tool to discuss the association between the child’s problem behaviour and the father’s business
travel, and to brainstorm with the family logically linked strategies to improve the child’s behaviour when the father went on a business trip.

4.4 Implications

Results of this study offer three implications for practitioners who are involved in behavioural interventions for children with ASD and sleep-related problem behaviour: (a) an enhanced model of support for children with ASD and sleep problems; (b) a method for addressing the introduction of non-evidence based interventions concurrent with behavioural interventions; and (c) a mindfulness-based method for interventionists to maintain their commitment to families in the face of unexpected delays and obstacles.

4.4.1 An Enhanced Model of Support for Children with ASD and Sleep problems

This study applied a family-centered PBS approach to the amelioration of sleep problems in a child with autism that integrated evidence-based practices from the research on sleep problems in children with autism with the emerging evidence-based practices of PBS. This approach represented an adaptation of a family-centered, PBS approach described by Lucyshyn, Kayser, Irvin and Blumberg (2002); Buschbacher, Fox and Clarke (2004); and Binnendyk and Lucyshyn (2009) to the needs of a family raising a child with autism who engaged in sleep problems in the home.

This study illustrated how families can take the lead in defining a valued and successful bedtime routine. By collaboratively defining the bedtime routine, practitioners are able to make accommodations for individual family systems and culture. In this case, the mother was primarily responsible for implementing the bedtime routine. The father’s business travel schedule was such that he was away from the home 2-3 weeks at a time, preventing him from actively participating in the bedtime routine on a consistent basis. Initially, the envisioned routine included both the mother and the father carrying out elements
of the routine together. However, due to the father’s business travel, this was not possible. Given this ecology, the mother took on the role of primary implementer of the bedtime routine, and the envisioned routine was revised.

This study also demonstrated the value of intervening in the context of an activity setting. The features of an activity setting enable the selection of child and family goals that are aligned with the goals and values that are important to the family. In addition, the activity setting allows practitioners to accommodate natural variations in the bedtime routine. For example, when the grandparents babysat the child, they took one step back in the fading process, and when the parents went on vacation, the child slept with the parents. These accommodations were acceptable to the parents, minimized sleep disruptions that might have arose in untrained environments (i.e., different people and different locations), and did not impede the child’s progress in the bedtime routine. The activity setting as a unit of analysis allows practitioners to understand and accommodate natural variations in a routine over time (Lucyshyn et al., 2009). As illustrated in this study, doing so contributed to the sustainability of improvements in a bedtime routine across 11 months of intervention.

This study also demonstrated the value of broadening assessment measures to include an assessment of the family’s ecology. An assessment of a family’s ecology can: (a) contribute to the development of trust and a collaborative partnership between the interventionist and the family (Lucyshyn & Albin, 1993); and (b) build on a family’s strengths, resources, social supports and child and family goals. For example, in the family ecology assessment the parents informed me that one of the family’s strengths was that family time was very valuable and that they made time to engage in family activities together. Based on this knowledge, I was able to better understand and accommodate the
family when they requested to take a break when the father returned from an extended business trip in order to reconnect.

A collaborative partnership also was an essential component of the success of the intervention. During this study, my partnership with the mother was essential in being able to overcome obstacles that arose. For example, our partnership provided the mother with the confidence that she needed to overcome her hesitancy to not only progress to the final step in the fading hierarchy, but to also embrace the strategies that she had acquired and undertake the final step without any direct training. According to Carr et al. (2002), effective, meaningful, acceptable and sustainable outcomes are more probable if all of these features of PBS are integrated into a behavioural intervention.

4.4.2 Addressing the Introduction of Non-evidence based Interventions Concurrent with Behavioural Interventions

For families that introduce non-evidence based interventions concurrent with behavioural interventions, this study suggests a method for understanding and addressing the non-evidence based intervention if it proves to be an obstacle to the child’s and family’s continued progress. When a non-evidence based intervention is brought to the interventionist’s attention, the interventionist needs to assess whether it is benign and thus will have no effect on the child’s progress, or whether it is an obstacle and thus needs to be addressed within a problem solving process. If the non-evidenced based intervention is an obstacle, then interventionists can: (a) initiate a problem solving dialogue with the family; (b) bring to their attention the association between the introduction of the non-evidence based intervention and problematic behaviour; and (c) work together to identify a logical solution given the evidence presented. For example, after I brought to the mother’s attention the association between the blanket and an increase in the mother’s reports of sleep disturbances,
she agreed to suspend use of the weighted blanket for a few days and observed whether the
child’s behaviour improved. When the child’s behaviour immediately improved, she
recognized that it wasn’t helpful in improving the child’s sleep and that this non-evidence
based intervention was an obstacle to the child’s progress.

The GAPS diet represented a more difficult obstacle to address. In such a case, a
more involved and systematic problem solving dialogue may be required. First, I would
recommend that interventionists normalize for the family the experience of adopting a non-
evidence based intervention. This may involve informing the child’s parents that families of
children with autism, on average, adopt seven concurrent interventions, some of which have
no empirical support. Next, it is important to help the family recognize the impact of the non-
evidence based intervention on the child’s progress. If the parent is still committed to
pursuing the non-evidence based intervention, then professionals can work with parents to
collaboratively minimize the effect of the intervention on the child’s behaviour. A functional
analytic process provides an avenue for doing so. In this way, the non-evidence based
intervention can be viewed as a setting event and the researcher and family can go through a
process of what can be done to minimize the effect of this setting event on the child’s
behaviour. It was through this logic that the mother agreed to re-introduce preferred foods
into the child’s diet that were consistent with the GAPS protocol, and to ensure that the child
had access to these foods on a daily basis. Fortunately, this diet included gradually shifting
back to a more normal, less restrictive diet, which enabled the mother to bring back some of
the child’s previous and preferred foods. Additional strategies also were put in place to lessen
the aversiveness of the diet for the child. The mother agreed to increase positive
reinforcement and decrease demands during the child’s day to moderate the aversiveness of
the diet on the child’s quality of life and to minimize common triggers for problem behaviour while the diet was in place. The collaborative nature of the partnership, combined with the functional analytic perspective of viewing the non-evidence based intervention as a setting event, allowed us to make these compromises.

I would also recommend that to proactively address these obstacles, interventionists establish clear guidelines and boundaries prior to the initiation of the behavioural sleep intervention, including giving families information resources on how to identify and differentiate between an evidence-based and non-evidence based interventions, and examples of non-evidence based interventions that may be presented by professionals over the course of the intervention. If families, despite being given this information, choose to adopt non-evidence based treatments, it is important to anticipate and recognize problems associated with the treatments as they arise. Furthermore, interventionists also must be prepared to be open-minded and flexible in regard to making accommodations so that family members remain valued and respected partners in the clinical support process (Lucyshyn et al., 2002).

4.4.3 Interventionists Maintaining their Commitment to Families in the Face of Unexpected Delays and Obstacles

The process that I went through in the midst of the delays and obstacles may suggest a process of responding to the stress of supporting challenging children and/or difficult families. Working with families can be stressful, and when delays and obstacles are encountered, this may lead to interventionists losing confidence in their ability to promote change in families, and in a family’s willingness to change. In my own experience, a process of acceptance and commitment similar to the mindfulness-based Acceptance and Commitment Therapy (ACT), described by Hayes and his colleagues (2004), allowed me to overcome this. ACT may provide a way for interventionists to work through these delays
and obstacles, and the associated cognitive difficulties that they may encounter, in order to return to the overarching goal of supporting the child and the family and continue providing support.

ACT is part of a larger movement in the behavioral and cognitive therapies toward the use of mindfulness and acceptance (Hayes, Follette, & Linehan, 2004). The purpose of ACT is to enhance psychological flexibility – the ability to contact the present moment more fully and to change or persist in behavior when doing so is consistent with the values a person holds (Hayes et al., 2004). Early evidence indicates that ACT has a broad range of clinical applications, including workplace stress and anxiety (Strosahl, Hayes, Bergan, & Romano, 1998). Specifically, ACT increases both the acceptance of workplace anxiety and stress and the positive work behaviours that are suppressed by these emotions (Bond & Bunce, 2000). Stress has negative effects on both the well-being of practitioners and the children and families that they serve. Namely, research indicates that practitioners under stress: (a) interact less frequently with clients; (b) engage in fewer positive interactions with clients; and (b) display increased absenteeism and intentions to leave organizations (Hastings, Horne & Mitchell, 1993). ACT may be particularly suited to working through the stress and anxiety of working with challenging children and/or difficult families as it emphasizes: (a) commitment to goals; and (b) acceptance of undesirable psychological events that stem from unalterable work circumstances (Hayes, Follette, & Linehan, 2004).

In this study, each time that I experienced a delay or an obstacle, I went through a process of accepting it and recommitted to the family. During this process, I maintained my commitment to larger goal of helping the family, and the specific goals that were established at the start of the intervention. This process greatly reduced the stress of the delay or obstacle.
that was encountered, and helped me overcome my own doubts and fears. Without this process, it is likely that I would have withdrawn from the family, and missed the opportunity to support the family and work through the obstacles and delays. In addition, I also suppose that this had the collateral effect of strengthening my relationship with the family.

In supporting families of children with disabilities and problem behaviour in the home, developing psychological flexibility through a process of acceptance and commitment can strengthen interventionist in their adherence their professional values and achievement of their professional goals to promote positive change in family’s lives.

4.5 Limitations

Although this study offers a number of contributions and implications, it is not without limitations. Several limitations need to be acknowledged: (a) research design; (b) external validity; (c) time and effort required; (d) absence of parent-report data during portions of the study; (e) collection of parent data without interobserver agreement; and (f) absence of a maintenance and generalization phase.

4.6 Research Design

Although there was an immediate, dramatic, and stable improvement in the child’s sleep behaviour and his participation in the bedtime routine, one must use caution when interpreting these results. The quasi-experimental, single-subject research design employed controls for some threats to internal validity, but the design cannot entirely rule out the potential effects of history and maturation. However, as noted by Kazdin (1992), when immediate and large changes in behaviour are evidenced within a case study design, history and maturational factors are unlikely to account for the results.
4.6.1 External Validity

The results of this study, although promising, are based on support to one child and family within one routine. For this reason, the ability to draw conclusions about the potential impact of the family support process with other families of children with ASD and sleep problems is limited. Thus it is necessary to be cautious in extrapolating these results to other children with sleep problems and their families.

4.6.2 Time and Effort Required

At the outset of the study, neither the family nor I anticipated the length of time of time that would be required to go through the fading steps, for the child to fall asleep independently and to promote meaningful change. Although the data suggest that the support process was effective for the child and his mother, it cannot be characterized as efficient or inexpensive in terms of time and effort. Before each probe observation session, I met with the mother 2-4 times to conduct training sessions that lasted approximately 2.5 hours. In addition, problem solving meetings were scheduled when obstacles arose and lasted approximately 2 hours each. The outcomes summarized required over 11 months. Key factors that contributed to this lengthy time period included the delays and obstacles described above that were encountered during intervention. Delays were events in the family’s life that occurred across the course of the study, and included: (a) family vacations, holidays and social gatherings; (b) parent and child illness; and (c) major changes and transitions in the child’s life (i.e., going to preschool). Obstacles were: (a) the father’s business travel affecting the child’s sleep; (b) the mother adopting non-evidence based treatments that interfered with progress; and (c) the mother’s hesitancy to progress through the fading steps once she was successfully sitting in a chair outside the child’s door.
Although the mother stated in the debriefing interview that she would have likely adapted if pressure was placed on her to go at a more expedited pace, she also stated that she needed the time in order to regroup before the next phase of the intervention. All things considered, I decided to err on the side of caution. This may have contributed to the extent of the delays but also was associated with the family attaining most of their vision of the bedtime routine.

The time and effort required to achieve meaningful outcomes with families should not deter researchers from pursuing research with such families. Durand and Rost (2005) make the case that too often studies involve families that present researchers with little challenge. This leaves researchers wondering whether the intervention would have been as effective with a wider population of families. To minimize the stress that may arise as a result of the additional time and effort that may be required when working with more challenging families, interventionists’ use of acceptance and commitment therapy techniques is recommended.

4.6.3 Absence of Parent-report Data during Portions of the Study

With the exception of co-sleeping, there were no data recorded in the mother’s semi-structured sleep diary on the child’s specific sleep behaviours prior to the introduction of the intervention phase. During baseline, the mother did not gather data on the frequency of night wakings, the duration of night wakings and the frequency of problematic night waking. These data were not collected because the mother co-slept with the child in the parent’s bedroom during baseline. Thus, sleeping through the night data during baseline would not be comparable to sleeping through the night data during intervention. In addition, to request that the mother attempt to keep the child in his own bed throughout the night without support would have placed the child and parent at significant psychological and physical risk.
Additionally, during the check-in phase of the fading process (i.e., the mother leaving and briefly checking in at 5-15 minute intervals), latency to falling asleep data was not collected because the mother was no longer able to accurately determine when the child fell asleep. Because baseline data were not gathered on latency to falling asleep, frequency of night wakings and duration of night wakings, no conclusions can be made in regard to the efficacy of the PBS approach for improving these aspects of the child’s sleep behaviours.

4.6.4 Collection of Parent data without Interobserver Agreement (IOA) Data

Although interobserver agreement data (IOA) were collected on probe observation session data, IOA data were not collected on data reported by the mother in the semi-structured sleep diary. For this reason, these data should be viewed with caution. However, there is some evidence to support the reliability of parent completed sleep diaries. Durand and Mindell (1990) videotaped their participant’s bedtime routine on a weekly basis to assess both the reliability of the data collected and the parent’s compliance to the intervention and found no systematic bias. Evidence of the reliability of data collected by parents exists as well in other areas of the behavioural intervention literature. For example, Piazza-Waggoner, Driscoll, Gilman and Powers (2008) conducted a comparative evaluation of parent report and direct observation of mealtime behaviors in young children with cystic fibrosis and found significant agreement between the two methods for child and parent behaviors at mealtimes. Nevertheless, the collection of interobserver agreement data is important to control for the quality of sleep data collected and would have strengthened the internal validity of the study.

4.6.5 Absence of a Maintenance and Generalization Phase

Time constraints prohibited the collection of maintenance and generalization data, or follow-up data. Without maintenance and generalization data, this study does not speak to the
issue of generalizability or durability. In order to assess the durability of improvements in child sleep behaviour, data should be collected for months, or better yet, years post-intervention (Carr et al., 1999). Although this study did not provide evidence of generalizability or durability, a few factors suggest that the family is in a good position to maintain treatment gains. First, high social validity and goodness-of-fit ratings suggest that the mother is likely to use the plan for a prolonged length of time (Lucyshyn et al., 2002). Second, by the end of the study, the mother reported to have more energy and motivation to support her son during the bedtime routine, and expressed confidence in being able to train the child’s babysitter to implement the routine.

4.7 Recommendations for Future Research

This study and its preliminary results are the first to investigate whether a family-centred, PBS approach may be effective, feasible, and acceptable for a family with a child with ASD and sleep problems. First, research is required to investigate a functional relationship between the efficacy of the approach and child and family outcomes. The current study employed a single-subject case study design. Future research should employ a true experimental research design, such as a multiple-baseline design across subjects. Second, replication is also needed to establish the external validity. External validity would be enhanced if the efficacy of the process were demonstrated with children of different ages, children with ASD and different levels of functioning, children with different types of sleep problems, and families with different challenging issues (e.g., low socioeconomic status, single-parent, different mental health problems). Third, future research should investigate the extent to which the family-centred approach, implemented in a valued bedtime routine can be generalized to different people (e.g., a father, a babysitter, grandparents) and sleep
environments (e.g., a friend’s house, a hotel). Lastly, future research should collect long-term follow-up data to assess the durability and sustainability of the approach. Sleep problems in children with autism are persistent and can tax even the most committed and competent of families to maintain the intervention over a long period of time. Therefore, it is important to evaluate sleep interventions a substantial amount of time beyond direct treatment to assess the durability and sustainability of treatment effects.

4.8 Conclusion

This study examined five questions: (a) Is there an association between the implementation of a family-centered PBS plan and improvements in sleep behaviour in a child with autism?; (b) Is there an association between the family-centered, PBS approach and improvements in family quality of life as measured by *The Beach Centre Family Quality of Life Survey* (Beach Centre, 2001)?; (c) How do participating parents rate the social validity of the family-centered, PBS approach to sleep problems?; and (d) How do participating parents rate the goodness-of-fit of the behaviour support plan to the bedtime routine and overall family ecology?

First, the results indicated that a family-centred, PBS approach was associated with substantial improvements in a child with autism’s sleep problems and successful participation in a valued bedtime routine. Second, due to the absence of a maintenance and generalization phase, no firm conclusions can be offered regarding sustained improvements in child sleep behaviour for a protracted period of time. However, improvements in child sleep behaviour were sustained for 11 months during the intervention phase. Third, the results of the study indicate only modest gains in the family’s quality of life. Fourth, results of the social validity data indicate that the implementation of a family-centred PBS approach
corresponded to the mother viewing the intervention as important and acceptable in regards to goals, procedures and outcomes. Fifth, results of the goodness-of-fit data indicated that the mother viewed the intervention as having a good contextual fit with the family’s goals, expectations, resources and abilities.
References


supports for students with problem behaviors: Designing positive behavior support plans (pp. 334-358). New York: Guilford Press.


Appendices

Appendix A  Consent Form

April 20, 2011

Dear Parent/Guardian:

The purpose of this letter is to inform you of an opportunity to participate in a research study whose purpose is to help families of young children with autism who engage in problem behaviour during bedtime. The study is entitled, “A family-centred, Positive Behaviour Support Approach to Sleep Problems in Children with Autism.” The study will be conducted by the University of British Columbia. The Principal Investigator (PI) of the study is Joseph Lucyshyn, Associate Professor in the Faculty of Education of the University of British Columbia. The graduate student researcher is Rachel Zylka. The research study is for the fulfillment of degree requirements for the Master of Arts degree.

The purpose of the study is to examine the acceptability and effectiveness of a family centered approach to behaviour support with families of children with developmental disabilities who engage in problem behaviour during bedtime. The approach is based on best practice in positive behaviour support with families of children with developmental disabilities. The approach emphasizes the development of a collaborative partnership with family members and the design of positive behaviour supports that are both effective and a good fit with family life. The study will evaluate the extent to which the approach:

1) improves child behaviour during the bedtime routine
2) promotes the child’s successful participation in the bedtime routine;
3) helps family members successfully support the child with a disability; and
4) improves the quality of life of the child with a disability and the family as a whole.

Participation in the study would involve you and your family collaborating with members of the research team in four steps of the family support process, and in four research activities. The steps of the family support process are:

1) comprehensive assessment of child problem behaviour and family ecology;
2) collaborative development of a positive behaviour support plan;
3) implementation support to help families use behaviour supports in the bedtime routine; and
4) follow-up support.

Research activities include:

1) preliminary assessment to define the bedtime routine and to confirm child problem behaviour;
2) videotaped observations in the bedtime routine, under conditions that may produce problem behaviour, to confirm the purpose of problem behaviour;
3) videotaped observations in the bedtime routine; and
4) assessment of family quality of life.

Research and family support activities will occur over a 5 to 6 month period. During the first 4 to 5 months, your child and family will be involved in support and research activities for approximately 2 to 4 hours per week. This will vary based on family available time and need. During the final 1 or 2 months of the study, the child and family’s involvement will decrease to approximately 1 to 2 hours per week. Support activities will include conducting assessments, collaboratively designing a behaviour support plan, and helping families implement the plan in the bedtime routine. All activities will be scheduled on a day and at a time that is convenient for family members.

Families who choose to participate may experience four benefits. First, the child’s problem behaviour may decrease to near zero levels in the bedtime routine. Second, the child may develop new behaviours and skills that help him or her participate in the bedtime routine. Third, family members may enhance their parenting skills. A potential fourth benefit is that other families who have children with disabilities may be helped through the sharing of knowledge gained in this study.

If you are interested in participating in the study, or learning more about the study, please contact Joe Lucyshyn at (xxx) xxx-xxxx. You may also contact Rachel Zylka at (xxx) xxx-xxxx. Alternatively, you also may contact the agency representative who gave or sent to you this introductory letter. At that time, if you give the agency representative permission to release your name and phone number, Rachel Zylka will contact you by telephone to answer any questions that you may have. In any event, thank you for your time and consideration.

Sincerely,

Joseph M. Lucyshyn, Ph.D.
Associate Professor
Faculty of Education
University of British Columbia

Rachel Zylka, B.A.
Graduate Student Researcher
Faculty of Education
University of British Columbia
Appendix B Prescreening Interview

Positive Behaviour Support Approach to Sleep Problems in Children with Autism
Telephone Pre-Screening

Parent name: ___________________________  Phone # __________________
Date contacted: __________________________

This is a one year research project designed to investigate an approach to behavioral family intervention that seeks improve sleep problems in children with autism.

The study is recruiting families that meet the following criteria:

- Have a child with a formal diagnosis of autism
- Focus child is between three and eight years old and lives in a two parent household
- Both parents/guardians speak English proficiently
- Focus child engages in observable problem behavior during bedtime
- Parents do not perceive themselves to be in a “crisis” due to the child’s behavior or other family problems
- Parents/guardians agree to have an observer videotape child-parent interactions in typical routines in the home
- Both mother and father are willing to act as an interventionist with their child
- Family is willing to participate in the study for at least one year
- Family is planning to stay in the same locale over the next year

Do you have questions about these criteria? Do your child and family meet the criteria I’ve described?

I’d like to ask some questions about your child, your family and your reasons for wanting to participate in this study

| Please describe your child: age, disability, school program or other services |
| Please describe your family: members, occupations, ability to participate in a study |
| Briefly describe the problem behaviors your child displays |
| Briefly describe the sleep routine during which |
problem behaviors are most likely to occur

| Briefly describe your reasons for wanting to participate in this study |
| Tell us about any questions or concerns you have about participating in a study |

The next step is screening; screening involves a researcher making an appointment to visit your home, obtain your consent to conduct interviews and observations that will help us confirm that your child and family are eligible candidates for participation in the study.

Following screening, two families will be selected to participate in the study.

The research activities will consist of the following:

- A comprehensive functional assessment of the focus child’s problem behavior will be conducted
- An assessment of the problematic sleep routine will be conducted. Family members will be asked to describe aspects of the routine that are currently not going well, but which they would like to improve. This routine will be targeted for intervention.
- The researchers will work with family members to develop a behavioral support plan, and will train family members to implement the plan.
- The researchers will videotape the problematic sleep routine before and after the behavior support plan is implemented and will collect other data about how the plan is working. (only the researchers will view the videotapes and they will be stored in a secure location, no confidential information will be shared with anyone outside the research team)
- Behavioral support plans will be updated and improved as needed

- A benefit of participation in this study is that families will receive up to 1 year of behavioral consultation and support in the problematic sleep routine identified.

Do you have any questions?

Are you interested in participating in the screening process?

Thank you for participating in this pre-screening interview. A researcher will contact you within the next 7–10 days.
Appendix C  Consent Form for Participation in Screening Process

CONSENT FORM: PARTICIPATION IN SCREENING PROCESS
Positive Behaviour Support Approach to Sleep Problems in Children with Autism

Principal Investigator: Joseph M. Lucyshyn, Ph.D.
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, BC V6T 1Z4

Graduate Student Researcher: Rachel A. Zylka

Dear Parent/Guardian:

The purpose of this form is to request consent for your, for your child with a disability, and for other family members’ (focus child’s brother or sister) participation in a screening process for a research study. The study will be conducted in the Faculty of Education of the University of British Columbia. Joseph Lucyshyn is the Principal Investigator. The Graduate Student Researcher is Rachel Zylka. The research study is for the fulfillment of degree requirements for the Master of Arts degree. I am inviting your family to participate in the screening process because a representative of a local social service agency has recommended your child and family’s participation. After reading the consent form, if you have any questions, I will be happy to answer them to ensure that the screening procedures are fully understood.

PURPOSE OF STUDY

The purpose of the study is to examine the acceptability, effectiveness and sustainability of a comprehensive approach to behaviour support with a family of a child with ASD, who also displays one or more sleep problems. The approach is based on best practices in positive behaviour support (PBS) with families. It emphasizes a collaborative process in which family members and the graduate student researcher work together in equal partnership to improve the sleep behaviour of the child with ASD, and the quality of life of the family as a whole. The study will evaluate the extent to which positive behaviour support plans:

1) Improve child behaviour and parent-child interaction during the bedtime routine;
2) Promote the child’s successful participation during the bedtime routine;
3) Empower parents and other family members to successfully support the child; and
4) Enhance the quality of life of the child with a disability and his or her family.
1. SUMMARY OF FAMILY SUPPORT AND RESEARCH ACTIVITIES

Participation in the project will involve parents and other family members collaborating with members of the research team in four family support activities and four research activities.

The four family support activities are:

1) Comprehensive assessment;
2) Development of positive behaviour support plans;
3) Implementation support to help parents and other family members implement the behaviour support plans; and
4) Follow up support.

The four research activities are:

1) Preliminary assessments to define routines and confirm presence of problem behaviour in routines;
2) Videotaped observations, under conditions that may produce problem behaviour, to verify the purpose of problem behaviour;
3) Videotaped observations in family routines to measure outcomes; and
4) Assessment of overall family quality of life.

Research and family support activities will occur over a 5 to 6 month period. During the first 4 to 5 months your child and family will be involved in support and research activities for approximately 2 to 4 hours per week. This will vary based on family available time and need. During the final month of the study, the child and family’s involvement will decrease to approximately 1 to 2 hours per week. Research and family support activities are described below:

2. CRITERIA FOR PARTICIPATION IN STUDY

Before a family can participate in the study, we first need to confirm that the child and family meet the criteria for participation. A total of two (2) families will participate in the project. The families will meet the following criteria:

- Have a child with a formal diagnosis of autism;
- Focus child is between three and eight years old and lives in a two parent household;
- Focus child engages in observable problem behaviours during bedtime;
- Parents/guardians agree to have an observer videotape child-parent interactions during the bedtime routine;
- Both mother and father are willing to act as an interventionist with their child;
- Family is willing to participate in the study for at least one year; and
- Family is planning to stay in same locale over the next year.
3. SCREENING PROCESS

We have developed a screening process to find out if your child and family are eligible to participate in the study. We will first contact you by telephone, review the criteria for participation, and answer any questions you may have. We will then decide together whether to proceed with the screening process. The specific steps in the process are described below.

1. Preliminary interview. We will first meet with you in your home or a place that is more convenient for you and conduct a preliminary interview. The interview is focused on understanding your child’s problem behaviours in the home and community. The interview will take approximately one hour.

2. Preliminary observations. If the interview indicates that your child is a good fit for the study, then we will request permission to conduct observations in the home. With your permission, I will observe you and your child during the bedtime routine in which problem behaviours regularly occur. During the observation, I will use an observation form to gather data about child problem behaviours. A minimum of 2 to 4 observations will be conducted. Each observation will last between 3 and 15 minutes.

3. Informed consent for study participation. If the observations confirm the presence of durable problem behaviours in four family routines in the home and/or community, then we will invite you to participate in the study. At that time, we will ask you to read and sign an informed consent letter for participation.

POTENTIAL RISKS AND SAFEGUARDS

If you agree to participate and permit your child and family to participate in the screening process, you will need to consider four potential risks: (1) physical; (2) psychological; (3) legal; and (4) loss of confidentiality.

1. Physical Risk Because your child engages in problem behaviour, there is more than a minimal risk that you, your child, or another family member may experience a physical injury during the screening process. Every precaution will be taken to minimize this risk:
   a. Members of the project team have extensive experience working with children who engage in problem behaviour in home and community settings.
   c. Observations will be terminated if your child begins to engage in medium or high intensity problem behaviour.
   d. As needed, project staff will be available to assist you, your child, and other family members during observations.

2. Psychological Risk Because your family will be observed during home and community routines, you, your child, or other family members may experience psychological risk. That is, you, your child, or other family members may feel some discomfort or stress during this activity. Several steps will be taken to guard against this risk:
   a. During observations, the observer will maintain a low profile and not call attention
to him or herself.
b. You or other family members can terminate an observation at any time.
c. Preliminary interviews will be conducted at a time and place that is convenient for you and your family.

3. **Legal Risk** A potential but minimal risk relates to the legal requirements around reporting abuse if it is witnessed. If members of the research team witness any abuse of the focus child by any person, they will have to report it to the appropriate provincial authorities. This risk will be guarded against in the following ways:
   a. If abuse is observed, you will be informed and invited to participate in reporting the incident. The research team also will offer your family counselling support

4. **Loss of Confidentiality** There is a risk that you, your child, or another family member may experience a loss of confidentiality. To guard against this risk we will:
   a. change the names of all persons, places, and programs described on assessment forms;
   b. allow access to information only to members of the research team;
   c. keep all data, notes, and videotapes in a locked file in a secure office; and
   d. destroy all data, collected solely for the purposes of screening, 5 years after the study is completed.

4. **POTENTIAL BENEFITS**

By participating in the screening process, you and your child will experience one of two potential benefits. These are listed below.

1. **Participation in family support research study.** If the screening process indicates that your child is a good fit for the family support study, you will be invited to participate in the research study. There are five specific benefits of participation:
   a. your child’s behaviour problems may decrease to near zero levels during the bedtime/sleep routine
   b. your child may develop new skills that help him or her participate in the bedtime/sleep routine.
   c. the quality of parent-child interactions may improve and your knowledge and skills in supporting your child may be enhanced.
   d. through participation other families who have children with disabilities may also benefit. This will occur by describing the study’s results in journals and at conferences.

However, because behavioural and quality of life improvements cannot be assured, it is possible that you and your family may not experience all of the benefits listed above.

2. **Assessment report and recommendations.** If the screening process does not indicate that your child is a good fit for the study, then we will provide you with three benefits:
   a. summary of the preliminary interview and/or observations;
b. recommendations for behaviour support that are based on the interview and/or observations; and referral to appropriate, alternative sources for family and behavioural support in your community.

ALTERNATIVES

If during the screening process, you choose not to participate in the study, we will refer you to appropriate, alternative sources for family and behavioural support in your community.

5. RIGHTS AS A RESEARCH PARTICIPANT

Your participation and that of your child and other family members is voluntary. Your decision whether or not to participate and to allow your child and other family members to participate will not have any effect on your child’s education, the provision of support from a community agency, or future opportunities for behaviour consultation and support. If you agree to participate and allow your child and other family members to participate, you are free to withdraw consent and refuse to continue your participation and that of your child and family. You may do so at any time without penalty or loss of benefits to which you, your child, or other family members are otherwise entitled. By signing the consent form, you do not waive any of your legal rights. If you have any questions, please contact Dr. Joseph Lucyshyn, Faculty of Education, University of British Columbia, 2125 Main Mall, Vancouver, B.C., V6T 1Z4, (xxx) xxx-xxxx. Alternatively you can also contact Rachel Zylka, Graduate Researcher, at (xxx) xxx-xxxx. If you have any concerns about your rights or treatment as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598. Your signature below indicates that you have received a copy of this consent form for your records. Your signature indicates that you consent to your, your child with a disability and other family members (i.e., siblings) participation in the study.

Sincerely,

Joseph M. Lucyshyn, Ph.D.
Principal Investigator
Faculty of Education
University of British Columbia
CONSENT FORM FOR PARTICIPATION IN SCREENING PROCESS

Study Title: A Family-Centred, Positive Behaviour Support Approach to Sleep Problems in Children with Autism (the “Study”)
Principal Investigator: Joseph Lucyshyn, Ph.D. Faculty of Education, University of British Columbia
Graduate Student Researcher: Rachel Zylka, B.A., Faculty of Education, British Columbia

I have read and received a copy of this consent form and have had an opportunity to ask questions about the research project and the screening process. I have received an adequate description of the purpose, goals, and procedures of the screening process, and I consent to participate in the screening process. I understand that all information will be kept confidential, that my participation is voluntary, and that I may withdraw consent at any time and discontinue participation at any time without penalty or loss of benefits to which I am otherwise entitled, and that I am not waiving any legal claims, rights, or remedies. By signing below, I agree to participate in the screening process of the research study of parent-child interaction in family routines under the terms stated above.

_________ YES, I consent to participate in the screening process and give permission for my child with a disability and other family members (i.e., focus child’s brother and/or sister) to participate in the screening process.

_________ NO, I do not consent to participate in the screening process, and my child with a disability and other family members do not have my permission to participate in the screening process.

Focus Child’s Name:_______________________
Sibling’s Name:_______________________

6. Sibling’s Name:_______________________

Parent/Guardian Signature:________________________ Date:__________

Parent/Guardian Signature:________________________ Date:__________

Witness:_______________________________________ Date:____________

PLEASE RETURN THIS PAGE TO:
Joseph Lucyshyn, Ph.D.
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, B.C. V6T 1Z4
I have talked with your parents about a screening process. The screening process is the first step in a research project that you and your family might do with me. The purpose of the screening process is to find out if you and your family can participate in the research project. During the screening process, I will visit your home, talk with your parent(s), and observe you and your parents doing things together. I will observe you and your parents doing activities together in the home. For example, having dinner together or the time when you go to bed [role play observing the child and parent(s) around the dining room table].

The information from these talks and observations will help us decide whether you and your family will participate in the research project. During an observation, if you want me to stop, you just have tell your parents or me to stop. Also, anytime you want to stop the screening process (that is, stop me from coming over a few times to observe), then just tell your parents and I will stop. After we finish the talks and observations, we will be able to decide what to do next. If we invite you and your family to participate in the research project, then we will visit you more often and observe more often. At that time, we will help you and your family learn to do things together in the home or in the community. For example, we may help you and your family have dinner together at home or help you and a parent go to the grocery store together. Also at that time, we would use a video camera to observe [show video camera and role play videotaping] how you and your family are doing during these home or community activities. If we are unable to invite you and your family to participate in the study, we will give your family a summary of the interview and observations. We also will give them suggestions about how to help you participate in the home and community activities.

I am telling you what I will do, so that you can tell me whether you would like to participate in the screening process, or would prefer not to participate. If you choose to participate, then your parent(s) will sign their name below. Remember, you can change your mind and stop the screening process at any time.

Name of participant: ___________________________

__________ YES, I agree to participate in the screening process

__________ NO, I do not agree to participate in the screening process

Signed: __________________________ Date: __________

Witness: __________________________ Date: __________
We are interested in learning how to help your parents support (name of focus child) at home and in the community. We plan to do this by conducting a study. Before we can begin the study, we need to find out if _________ is eligible to participate in the study. We wish to do so by conducting a screening process with your family. We will interview your parents and observe _______ and other family members doing activities together in the home and community. For example, we may observe _______ having dinner together with family members, or observe _______ going to a grocery store with a family member.

We also would like to ask you to participate in some of these routines in the home and community. If you agree to participate, we will ask you to do what you typically do during these routines; that is, listen to your parents and cooperatively do the routine. We will make sure that while you and your family are doing these routines together, you and your family are safe.

When we begin, a person will visit your home to observe you, ________, and your parents in up to four routines. We will observe once or twice in each routine to find out if ________ engages in problem behaviour in these routines. When an observer is observing the routine and collecting data on problem behaviour, he or she will do his or her best to stay out of the way. Also, the screening data will only be shared with members of the research team.

If the screening process shows that______ is a good fit for the study, then we will invite your family to participate in the study. During the study we will help your family create a happier life for _______ and your family. We will do so by helping your family successfully support _______ in four valued routines in the home or community. If the screening process does not show _______ to be a good fit for the study, then we will give your parents a summary of the information that we gathered, and suggest to them some ways that they can support ________ ‘s participation in the routines that we observed.

While we are observing ________, you, and other family members, if you do not want to participate, just tell us. You won't get into any trouble. If you don't want to participate at all, you don't have to. Just say so. Also, if you have any questions about what you will be doing, or if you cannot decide, just ask us if there is anything you would like us to explain. If you want to try, please sign your name on the line below. Your parent(s) have already told us that it is alright with them if you want to participate in the screening process. Remember, you don't have to, and once you start you can rest or stop whenever you like.

Name of participant: ___________________________

__________ YES, I agree to participate
__________ NO, I do not agree to participate.

Signed:___________________________________ Date:__________
Witness:__________________________________ Date:__________
Appendix D  Consent Form for Participation in Study

CONSENT FORM

Positive Behaviour Support Approach to Sleep Problems in Children with Autism

Principal Investigator:  Joseph M. Lucyshyn, Ph.D.
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, B.C., V6T 1Z4

Graduate Student Researcher:  Rachel A. Zylka

Dear Parent/Guardian:

The purpose of this form is to request consent for your, for your child with Autism Spectrum Disorder (ASD), and for other family members’ (i.e., focus child’s brother and/or sister) participation in the research study. The study will be conducted in the Faculty of Education of the University of British Columbia. Joseph Lucyshyn is the Principal Investigator. The Graduate Student Researcher is Rachel Zylka. The research study is for the fulfillment of degree requirements for the Master of Arts degree. I am inviting your family’s participation because a representative of a local social service agency has recommended your child and family’s participation. After reading the consent form, if you have any questions, I will be happy to answer them to ensure that the procedures are fully understood.

PURPOSE OF STUDY

The purpose of the study is to examine the acceptability, effectiveness and sustainability of a comprehensive approach to behaviour support with a family of a child with ASD, who also displays one or more sleep problems. The approach is based on best practices in positive behaviour support (PBS) with families. It emphasizes a collaborative process in which family members and the graduate student researcher work together in equal partnership to improve the sleep behaviour of the child with ASD, and the quality of life of the family as a whole. The study will evaluate the extent to which PBS plans:

(a) improve sleep problems and parent-child interactions during the sleep routine;
(b) empower you and other family members to successfully support your child; and
(c) enhance the quality of life of your child with ASD and family.

FAMILY SUPPORT AND RESEARCH ACTIVITIES

Participation in the project will involve you and your family collaborating with the graduate student researcher in family support and research activities. Research and family support activities will occur over a 5-6 month period. During the first 4-5 months your child and family will be involved in support and research activities for approximately 2-4 hours per
week. During the final month of the study, the family would be involved in support and research activities for approximately 1-2 hours per week. Research and family support activities are described below:

Preliminary Assessment. Preliminary assessment activities will involve two interviews with you and other family members, with each interview lasting 1-2 hours. The purpose of the interviews is to develop a preliminary understanding about your child’s problematic sleep behaviours. Additionally, a sleep problem questionnaire will be completed. Following the interviews, we will conduct two to three pilot observations during the sleep routine. The purpose of these observations will be to verify the occurrence and purpose of problematic sleep behaviours. Each observation will last up to 15-20 minutes.

Comprehensive Assessment. First, a functional assessment interview (FAI) will be completed. This will involve one meeting of 1-2 hours in length. The assessment will help us develop a comprehensive understanding of the conditions that occasion problematic sleep behaviours and positive sleep behaviours. Second, we will complete a family ecology assessment. This will involve one meeting of 1-2 hours in length in which we will learn about your family’s strengths, social supports and resources, stressors and goals for your child and family.

Positive Behaviour Support Plan Design. Following each of the above assessment activities, we will collaborate with you to build a positive behaviour support plan for the problematic sleep routine. This will involve one meeting of 1-2 hours in length. During the planning meeting, family members and the graduate student researcher will review assessment information for a routine and build a support plan that fits well with the routine. The plan will be designed to improve child sleep behaviour, parent-child interactions, and the success of the routine.

Implementation Support. Training and support to help you and other family members implement the support plan during the sleep routine will occur approximately twice per week and involve 1-2 hours. During these meetings, the graduate student researcher will teach you and other family members how to implement support strategies with your child.

Maintenance Support. After you have succeeded in improving child sleep behaviour and parent-child interaction in the sleep routine, we will transition to a phase of research called maintenance support. During maintenance support, we will provide training and support as needed for one additional month.

Videotaped Observations in Home-based Sleep Routine. Videotaped observations in routines will occur an average of 1-2 times per week over a period of 11 weeks. During observation sessions, an observer will videotape your child and family’s participation in the sleep routine. Each observation session will last between 20-30 minutes.

POTENTIAL RISKS AND SAFEGUARDS
If you agree to participate and permit your child and family to participate, you will need to consider four potential risks: (1) physical; (2) psychological; (3) legal; and (4) loss of confidentiality.

(1) Physical Risk. Because your child engages in problematic sleep behaviour, there is more than minimal risk that you, your child, or another family member may experience physical injury during the study. Every precaution will be taken to minimize this risk, namely:

(a) members of the research team have extensive experience working with children who engage in problem behaviour in the home;
(b) behaviour support strategies will focus on preventing behaviour problems and on teaching positive behaviours that are designed to replace problem behaviours; and
(c) observation sessions and training support activities will be terminated if your child begins to engage in medium or high intensity problem behaviour.

(2) Psychological Risk. Because your family will be observed during the sleep/bedtime routine and will participate in training and support activities, you, your child, and other family members may experience or feel some discomfort or stress during activities. Several steps will be taken to minimize this risk, namely:

During observation sessions, the observer will maintain a low profile and not call attention to him or her self. You or other family members can terminate an observation session at any time. “Family-friendly” features of the support process should help to reduce stress that may be associated with the study.

(3) Legal Risk. A potential but minimal risk relates to the legal requirements around reporting abuse if it is witnessed. If members of the research witness any abuse of the focus person by any person, they will have to report it to the appropriate provincial authorities. This risk will be minimized in the following ways:

The study focuses on providing family members with positive, non-punitive ways to prevent and manage child problem behaviour. Family members who develop these skills are unlikely to engage in child maltreatment. If abuse is observed you will be informed and invited to participate in reporting the incident. The research team will also offer your family counseling support.

(4) Loss of Confidentiality. There is a risk that you, your child, or another family member may experience a loss of confidentiality. This risk will be guarded against by:

(a) changing the names of all persons, places, and programs described in the study;
(b) allowing access to information only to members of the research team; and
(c) keeping all data, notes and videotapes in a locked file in a secure office.

POTENTIAL BENEFITS
By participating in the study, you, your child with ASD and other family members may experience three direct benefits and one indirect benefit. These are listed below:

(1) Your child’s behaviour problems may decrease to near zero levels during the bedtime/sleep routine
(2) Your child may develop new skills that help him or her participate in the bedtime/sleep routine.
(3) The quality of parent-child interactions may improve and your knowledge and skills in supporting your child may be enhanced.
(4) Through participation other families who have children with disabilities may also benefit. This will occur by describing the study’s results in journals and at conferences.

However, because behavioural and quality of life improvements cannot be assured, it is possible that you and your family may not experience all of the benefits listed above.

Your participation and that of your child and family members is voluntary. Your decision whether of not to participate and to allow your child to participate will not have any effect on your child’s education, provision of support from a community agency, or future opportunities for behaviour consultation and support. If you choose not to participate in the study, we will refer you to appropriate, alternative sources of family and behavioural support in the community. If you agree to participate and allow your child and other family members to participate, you are free to withdraw consent and refuse to continue your participation and that of your child and family. By signing the consent form, you do not waive any of your legal rights. If you have any questions, please contact Dr. Joseph Lucyshyn at (xxx) xxx-xxxx or Rachel Zylka at (xxx) xxx-xxxx. If you have any concerns about your rights or treatment as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services. Your signature indicates that you consent to your, your child with ASD, and other family members (i.e. siblings, if any) participation in the study.

Sincerely,

Rachel Zylka, B.A.
Graduate Student Researcher
Faculty of Education, University of British Columbia
CONSENT FORM

Study Title: A Family-Centred, Positive Behaviour Support Approach to Sleep Problems in Children with Autism (the “Study”)

Principal Investigator: Joseph Lucyshyn, Ph.D. Faculty of Education, University of British Columbia

Graduate Student Researcher: Rachel Zylka, B.A., Faculty of Education, British Columbia (together with the Principal Investigator, the “Investigators”)

Consent: I have read and fully understand the contents of the attached letter of request to participate in the Study, and I hereby consent to participate and hereby give permission for my child with autism spectrum disorder (ASD) and his or her siblings (as identified below) to participate in the Study.

I hereby consent to and authorize the release to the Investigators, from time to time, of the information contained in my child’s biographical records documenting birth date, most recent IQ score and test, diagnostic information and medical records, and such other information as the Investigators may request from time to time, for the purposes of the Study. I understand that all such information will be kept confidential except that the results of the Study may be published for academic purposes and in such event, the identity of the child and family will be kept confidential at all times.

I further understand that the Study will involve the Investigators video recording my family in our home. However, I also understand that I may request that the researchers stop such video recording at any time. I also understand that only the Investigators will have access to this material unless I give my specific permission for it to be viewed by any other person.

I fully understand that my participation in the Study and that of my family is entirely voluntary and that I, on behalf of my family, may withdraw this consent and terminate our participation in the Study at any time. I also understand that I will receive a copy of this signed consent form for my own records.

Focus Child’s Name: ____________________________________

Sibling’s Name (if any): ____________________________________

Parent/Guardian Signature: _______________________________ Date: _____________

Parent/Guardian Signature: _______________________________ Date: _____________

Witness: ____________________________________________ Date: _____________

PLEASE RETURN THIS PAGE TO:
Rachel Zylka, B.A., Graduate Student Researcher
### Appendix E  Steps Successfully Completed Data Collection

**Steps Successfully Completed Data Collection**

<table>
<thead>
<tr>
<th>Phase:</th>
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<tbody>
<tr>
<td>Observation Date:</td>
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<td>Date Coded:</td>
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**Going to Bed**

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<tbody>
<tr>
<td>1</td>
<td>Walk upstairs</td>
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<td>2</td>
<td>Undress</td>
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<tr>
<td>3</td>
<td>Take bath</td>
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<tr>
<td>4</td>
<td>Brush Teeth</td>
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<tr>
<td>5</td>
<td>Go to bedroom</td>
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<tr>
<td>6</td>
<td>Put on pajamas</td>
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<tr>
<td>7</td>
<td>Sit and listen to bedtime story</td>
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**Falling Asleep**

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<tbody>
<tr>
<td>1</td>
<td>Hug and/or kiss goodnight</td>
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<tr>
<td>2</td>
<td>Get into bed</td>
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<tr>
<td>3</td>
<td>Turn off light</td>
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<tr>
<td>4</td>
<td>Lay down</td>
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<td>5</td>
<td>Fall asleep</td>
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<tr>
<td>6</td>
<td>Stay in bed until 6:30am</td>
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</table>

**# of Steps Successfully Completed in Getting Ready**

**# of Steps Successfully Completed in Bedtime Steps**

**# of Steps Successfully Completed TOTAL**

<table>
<thead>
<tr>
<th>Percentage Completed</th>
<th>Percent Agreement</th>
<th>Coder Initials</th>
<th>Reliability Initials</th>
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</table>
### Appendix F  Sleep Diary

**Sleep Diary**

Child: ___________________  Date: ___________________

<table>
<thead>
<tr>
<th>Time put to bed</th>
<th>Time fell asleep</th>
<th>Co-sleeping? (Y/N)</th>
<th>Time awoke in morning?</th>
<th>Napping during the day?</th>
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**Night Wakings:** Check the box on the left for the number of night wakings that occur during the night, if any, noting the approximate duration of each night waking. Also, indicate whether you perceived the night waking to be problematic (i.e. disruptive).

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<thead>
<tr>
<th>Number</th>
<th>Duration</th>
<th>Was the night waking problematic? (Y/N)</th>
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### Appendix G  Parent Implementation Fidelity Data Collection

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<td>Observable Setting Event Strategies</td>
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<td>Warnings for transitions</td>
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<td>Visual schedule</td>
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<td>A large amount (5-10 minutes) of maternal attention before going to bed</td>
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<td>Engaging in calming/soothing activities before bed</td>
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<td>Social story</td>
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<td>Activities related to setting the stage for success when dad is away</td>
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<td>Visual contingency/discuss what will happen</td>
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<td>Behavioural momentum</td>
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### Teaching Strategies

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<td>Teach to ask for more time/to request attention</td>
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<td>Relaxation strategies</td>
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<tr>
<td>Use whole task instruction</td>
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<tr>
<td>Consequence Strategies</td>
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<tr>
<td>Provide reinforcement contingent on positive behaviour</td>
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<tr>
<td>Honour polite requests</td>
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<tr>
<td>If minor problem behaviour occurs, actively ignore and redirect</td>
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<tr>
<td>If major problem behaviour occurs during going to bed activities: actively ignore and redirect back to bed, return to using the fading technique</td>
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</table>
## Appendix H Social Validity Questionnaire

**Social Validity Questionnaire**

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<table>
<thead>
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<tbody>
<tr>
<td></td>
<td>Disagree</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td></td>
<td>Agree</td>
<td></td>
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</tbody>
</table>

Date: __________

Family member completing evaluation: ________________

1) The goals of the treatment plan are appropriate for my child.

Comments:

2) The goals of the plan are consistent with my family’s goals, values and beliefs.

Comments:

3) The strategies and procedures used are difficult to carry out.

Comments:

4) The strategies and procedures are effective in improving my child’s behaviour.

Comments:

5) The outcomes of the treatment effort are beneficial for my child.

Comments:

6) The outcomes of the treatment effort are beneficial to my family as a whole.

Comments:

7) The treatment effort has caused some unanticipated problems in our family.

Comments:

8) Training activities have been well organized, clear and helpful.

Comments:
Comments:

9) The person(s) providing technical assistance has shown respect for our family’s values and beliefs.

Comments:

10) Overall, this treatment effort has strengthened our family.

Comments:
Appendix I  Goodness-of-Fit Assessment

Goodness-of-Fit Assessment

Date: __________

Family member completing evaluation: ________________

<table>
<thead>
<tr>
<th>Question</th>
<th>Little</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>A lot</th>
<th>Can't Tell</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Do you believe that the treatment plan takes into account your understanding of your child (e.g., reasons for your child’s sleep problems, strategies that encourage positive behavior, child preferences)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>2) Does the plan address your highest priority goals (types of sleep problems, level of independence during the bedtime routine)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>3) Do you understand what you are expected to do with this plan?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>4) Are you comfortable with what you are expected to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>5) Do you understand what others are expected to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>6) Are you comfortable with what others are expected to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
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<tr>
<td>7) Does the plan for the bedtime routine disrupt the time of night to the point that stress or hardship will be created?</td>
<td>1</td>
<td>2</td>
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<tr>
<td>8) Does the plan recognize and build on your family’s strengths?</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<tr>
<td>9) All things considered, how difficult will it be for you to use this treatment plan for the bedtime routine?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>10) Do you believe the treatment plan will be effective?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>?</td>
</tr>
<tr>
<td>11) If the plan is effective, do you believe you can keep using the strategies for a long time (e.g., over one year) even though the experimenter will not be available as much? (some assistance by phone)</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tr>
</tbody>
</table>

Comments:
Appendix J  Beach Family Quality of Life Survey

FAMILY QUALITY
OF LIFE SURVEY

Developed by the Beach Center on Disability
The University of Kansas
in partnership with families, service providers and researchers.

For information, contact:
Jean Ann Summers, Ph.D.
Research Director, Beach Center on Disability
jsummers@ku.edu

Suggested reference for reports utilizing this instrument:


Beach Center on Disability
Making a Sustainable Difference in Quality of Life
FAMILY QUALITY OF LIFE

Thank you for agreeing to complete this survey. The survey is about how you feel about your life together as a family. We will use what we learn from families to inform policy makers and service providers for children and families.

Your "family" may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people

✓ Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and

✓ Who support and care for each other on a regular basis.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how Satisfied you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

✓ Checking the first square means you are very dissatisfied.

✓ Checking the fifth square means you are very satisfied.

Thank you so much for sharing your opinion with us!
### FAMILY QUALITY OF LIFE (cont.)

<table>
<thead>
<tr>
<th>How satisfied am I that...</th>
<th>Very Dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither</th>
<th>Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family enjoys spending time together.</td>
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<td>2. My family members help the children learn to be independent.</td>
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<td>3. My family has the support we need to relieve stress.</td>
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<td>4. My family members have friends or others who provide support.</td>
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<td>5. My family members help the children with schoolwork and activities.</td>
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<tr>
<td>6. My family members have transportation to get to the places they need to be.</td>
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<td>7. My family members talk openly with each other.</td>
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<td>8. My family members teach the children how to get along with others.</td>
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<td>9. My family members have some time to pursue our own interests.</td>
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<td>10. Our family solves problems together.</td>
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<td>11. My family members support each other to accomplish goals.</td>
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<td>12. My family members show that they love and care for each other.</td>
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<td>13. My family has outside help available to us to take care of special needs of all family members.</td>
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<td>14. Adults in our family teach the children to make good decisions.</td>
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<tr>
<td>How satisfied am I that...</td>
<td>Very Dissatisfied</td>
<td>Dissatisfied</td>
<td>Neither</td>
<td>Satisfied</td>
<td>Very Satisfied</td>
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<tr>
<td>15. My family gets medical care when needed.</td>
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<td>16. My family has a way to take care of our expenses.</td>
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<td>17. Adults in my family know other people in the children’s lives (friends, teachers, etc.).</td>
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<td>18. My family is able to handle life’s ups and downs.</td>
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<tr>
<td>19. Adults in my family have time to take care of the individual needs of every child.</td>
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<tr>
<td>20. My family gets dental care when needed.</td>
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<tr>
<td>21. My family feels safe at home, work, school, and in our neighborhood.</td>
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<tr>
<td>22. My family member with a disability has support to accomplish goals at school or at workplace.</td>
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<tr>
<td>23. My family member with a disability has support to accomplish goals at home.</td>
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<tr>
<td>24. My family member with a disability has support to make friends.</td>
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<tr>
<td>25. My family has good relationships with the service providers who provide services and support to our family member with a disability.</td>
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Appendix K  Debriefing Questionnaire

Family’s Experience/Involvement in Study
Open-Ended Questions

(1) Coming in to the study, what expectations did you have in terms of support, and also outcomes for your child?

(2) How did your experience of being in this study relate to these expectations?

(3) During the course of the study, there were a number of times when you asked us to pause, or take a break. Can you describe some of these experiences?

(4) What was your experience with how we responded to your requests to take a break?

(5) What might have been your experience if we said that we had to keep up a schedule, and pushed to continue support during these times?

(6) During the course of the study, you decided to add an additional intervention to your child’s routine. What was your experience with our response to this?

(7) In general, what was your experience of being involved in this study?

(8) What advice would you give to other families going into this type of intervention?

(9) If you were to provide any feedback that might help us when working with future families, what advice would you give?
Appendix L  Implementation Checklist

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<thead>
<tr>
<th></th>
<th>No in place</th>
<th>Partially in place</th>
<th>Fully in place</th>
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<tbody>
<tr>
<td><strong>Setting the Stage for Success</strong></td>
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<tr>
<td>1. Take out N’s daily nap or start N’s bedtime later so that he is so tired that it is easier for him to fall asleep on his own at night</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>2. Give N a verbal warning of transitions including: (a) from activity downstairs to going upstairs to take a bath, and (b) from getting out of the bath to getting on his pajamas</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>3. If N is over tired or hasn’t eaten properly, give N a choice of whether he will take a bath at night or in the morning</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>4. Provide N with a large amount (3-10 minutes) of maternal attention before going to bed (e.g., giving him a kiss or a hug)</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>5. Engage N in calming activities before bed and avoiding “academic” tasks and activities</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>6. Read a short story to N describing where everyone sleeps and what will be expected of him</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>7. Setting up a schedule with Dad 3-4 days before leaving that usually depicts: (a) when he is going away, (b) number of nights, and (c) when he is going to be back</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>8. Setting the stage for Success when Dad is away: (a) each time Dad comes back, have him bring back a small gift or present for N, (b) read N a story about Dad being away, (c) in the morning, review the calendar stating when Dad is away and when he’ll be back and cross out how many days until Dad returns; (d) set up a consistent schedule for contacting Dad and let him know when he will be receiving a phone call, a video phone call, or a picture from Dad; (e) when N talks about Dad or shows some mild anxiety, give N information and reassurance; (f) make a book to help N keep track of what N tells Dad and what Dad told N; (g) when N asks nicely for reassurance or information, immediately provide reassurance and information (e.g., remind N when he will get to talk to Dad, suggest writing in his notebook about what N is going to talk to Dad about); (h) if N shows problem behaviors occur related to anxiety about Dad, redirect N to alternative replacement behavior (e.g., prompt N to politely ask for information or reassurance about Dad); (i) if N shows problem behaviors occur related to anxiety about Dad (e.g., crying, being miserable, demanding that you stay with him), tell N you can’t talk about this and remove your attention for 1-2 minutes. After 1-2 minutes, redirect N to alternative replacement behavior</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td><strong>Preventing Problem Behavior</strong></td>
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</tr>
<tr>
<td>1. Use positive contingency statements (e.g., “If you get in the bath, you will get bath salts if you brush your teeth, you can listen to music if you put on your pajamas; we will read a story”)</td>
<td>na</td>
<td>1 2 3 4 5</td>
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</tr>
<tr>
<td>2. Provide N with lots of choice during the bedtime routine (e.g., number of minutes to engage in a preferred activity before transitioning to a new activity, which bathroom to use, which pajamas to wear, which books to read)</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>3. Remind N to ask for help with difficult/self-help tasks (e.g., putting on pajamas)</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>4. Show N a visual contingency and discuss with him what will happen in the morning if he falls asleep and stays in his room until 6:30am</td>
<td>na</td>
<td>1 2 3 4 5</td>
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</tr>
<tr>
<td>5. Before N goes to bed, remind briefly what N can do if he wakes up at night, and the relaxation strategies he can use (e.g., deep breathing, positive self-talk)</td>
<td>na</td>
<td>1 2 3 4 5</td>
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<tr>
<td>6. Gradually fade yourself out of N’s bedroom in phases. The phases include: (1) sitting beside N’s bed; (2) sitting in the hall; (3) sitting at the door in view with the door open; (4) sitting at the door in view with the door open and curtain closed; (5) sitting by the door but not in view; (6) sitting by the door but leaving for short periods of time; (7) leaving the room but doing regular check-ins beginning at short intervals, and gradually increasing the amount of time between check-ins. The criterion for moving to the next phase is that N is successfully falling asleep within 20 minutes, 2-3 nights in a row</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>7. Before leaving room, remind N to ask you to come back at next to you</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
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<tr>
<td>8. In phases 6 and 7 use a safety signal before leaving (e.g., “Go back to sleep, I’ll be back to check-in on you in a minute”)</td>
<td>na</td>
<td>1 2 3 4 5</td>
<td></td>
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</tbody>
</table>
## Teaching New Behaviours and Skills

<table>
<thead>
<tr>
<th>Step</th>
<th>1</th>
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<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td>1. Teach N to politely ask for mom to come back/give him attention</td>
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<tr>
<td>2. Teach N relaxation (e.g., deep breathing, tensing and relaxing muscles) and self-soothing strategies (e.g., “I’m safe, go back to sleep”, “Dad’s gone, it’s ok”) using direct instruction (i.e., modeling the words about his own sense of calmness, modeling deep breathing, and giving him praise for using these strategies)</td>
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<tr>
<td>3. Use whole task instruction by: (a) providing the minimum amount of assistance necessary for N to complete each step in the routine correctly; (b) gradually fade your assistance without loss of his ability to do each routine step correctly; (c) provide praise contingent on improvement in step completion and independence; and (d) gradually fade praise as N consistently shows cooperation and independence</td>
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## Rewarding Positive Behaviour

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<tbody>
<tr>
<td>1. Provide descriptive praise to N. (a) for transitioning to new activity and complying with routine-related tasks; (b) for lying down quietly in his bed during the current step in the fading strategy; and (c) in the morning for going to bed, falling asleep, waking up and going back to sleep at night by himself, and staying in his room until 6:30am</td>
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<tr>
<td>2. In the morning provide N a tangible reward (e.g., iPad) contingent on falling asleep on his own, going back to sleep by himself, and staying in his room until 6:30am.</td>
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## Removing Rewards for Problem Behaviour

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<tr>
<th>Step</th>
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</thead>
<tbody>
<tr>
<td>1. If minor problem behaviour occurs during preparation activities, actively ignore (refrain from commenting/discussing the behaviour) and redirect N to the current task/activity</td>
<td></td>
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<tr>
<td>2. If minor problem behaviour occurs during going to bed activities (e.g., N lightly kicks wall with foot): (a) ignore the behaviour and prompt N to politely request attention; and (b) introduce a safety signal. If N politely requests to come back, then honour his request.</td>
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<tr>
<td>3. If major problem behaviour occurs during going to bed activities: (1) walk N back to bed, guiding him from the back; (2) don’t make eye contact, talk to him or make any comments regarding his behaviour; (3) wait beside N’s bed until he is calm but don’t physically touch him; and (4) when he is calm, return to using the fading technique.</td>
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<tr>
<td>4. If N calls out in the middle of the night go and check in on him. Let him know that he is safe and that he should go back to bed. Re-implement the fading technique. Actively ignore any minor problem behaviours.</td>
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## Problem Behaviours

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fearful Talk</td>
<td></td>
<td></td>
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<tr>
<td>Protests</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Runs Away</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physically Protests</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screams/Cry/Tantrum</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gets out of bed</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Leaves room</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Laughs/giggles</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Phase in bedtime fading: __________

Number of minutes before N falls asleep: ________

## Social Validity

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goals of the bedtime routine are acceptable and important</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The strategies are useful and effective</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The strategies are difficult to use</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>N is successfully participating in the bedtime routine</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>We believe that the bedtime routines are now successful</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
## Appendix M  Albany Sleep Problems Scale

### ALBANY SLEEP PROBLEMS SCALE  
(ASPS)

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Does this person have a fairly regular bedtime and time when he or she awakens?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2.</td>
<td>Does this person have a bedtime routine that is the same each evening?</td>
<td></td>
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<tr>
<td>3.</td>
<td>Does this person work or play in bed, often right up to the time when he or she goes to bed?</td>
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</tr>
<tr>
<td>4.</td>
<td>Does this person sleep poorly in his or her own bed but better away from it?</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Does this person smoke, drink alcohol, or consume caffeine in any form?</td>
<td></td>
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<tr>
<td>6.</td>
<td>Does this person engage in vigorous activity in the hours before bedtime?</td>
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<td></td>
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<tr>
<td>7.</td>
<td>Does this person resist going to bed?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8.</td>
<td>Does this person take more than an hour to fall asleep but does not resist?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9.</td>
<td>Does this person awaken during the night but remain quiet and in bed?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>10.</td>
<td>Does this person awaken during the night and become disruptive (e.g., tantrums, oppositional)?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11.</td>
<td>Does this person take naps during the day?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Does this person often feel exhausted during the day because of lack of sleep?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Has this person ever had an accident or near accident because of sleepiness from not being able to sleep the night before?</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. Does this person ever use prescription drugs or over-the-counter medications to help him or her sleep?
   1 2 3 4

15. Has this person found that sleep medication does not work as well as it did when he or she first started taking it?
   Yes No/NA

16. If this person takes sleep medication, then does he or she find that he or she cannot sleep on nights without it?
   Yes No/NA

17. Does this person fall asleep early in the evening and awaken too early in the morning?
   1 2 3 4

18. Does this person have difficulty falling asleep until a very late hour and difficulty awakening early in the morning?
   1 2 3 4

19. Does this person wake up in the middle of the night upset?
   1 2 3 4

20. Is this person relatively easy to comfort from these episodes?
    Yes No/NA

21. Does this person have episodes during sleep in which he or she screams loudly for several minutes but is not fully awake?
    1 2 3 4

22. Is this person difficult to comfort during these episodes?
    Yes No/NA

23. Does this person experience sleep attacks (falling asleep almost immediately and without warning) during the day?
    1 2 3 4

24. Does this person experience excessively daytime sleepiness that is not accounted for by an inadequate amount of sleep?
    1 2 3 4

25. Does this person snore when asleep?
    1 2 3 4

26. Does this person sometimes stop breathing for a few seconds during sleep?
    1 2 3 4

27. Does this person have trouble breathing?
    1 2 3 4

28. Is this person overweight?
    Yes No

29. Has this person often walked while asleep?
    1 2 3 4

30. Does this person talk while asleep?
    1 2 3 4

31. Are this person’s sheets and blankets in extreme disarray in the morning when he or she wakes up?
    1 2 3 4

32. Does this person wake up at night because of kicking legs?
    1 2 3 4

33. While lying down, does this person ever experience unpleasant sensations in the legs?
    Yes No
34. Does this person rock back and forth or bang a body part (e.g., head) to fall asleep?  1  2  3  4
35. Does this person wet the bed?  1  2  3  4
36. Does this person grind his or her teeth at night?  1  2  3  4
37. Does this person sleep well when it doesn’t matter, such as on weekends, but sleep poorly when he or she “must” sleep well, such as when a busy day at school is ahead?  Yes  No
38. Does this person often have feelings of apprehension, anxiety, or dread when he or she is getting ready for bed?  1  2  3  4
39. Does this person worry in bed?  1  2  3  4
40. Does this person often have depressing thoughts, or do tomorrow’s worries or plans buzz through his or her mind when he or she wants to go to sleep?  1  2  3  4
41. Does this person have feelings of frustration when he or she can’t sleep?  1  2  3  4
42. Has this person experienced a relatively recent change in eating habits?  Yes  No
43. Does this person have behaviour problems at times other than bedtime or upon awakening?  Yes  No
44. When did this person’s primary difficulty with sleep begin?
45. What was happening in this person’s life at that time or a few months before?
46. Is this person under a physician’s care for any medical condition? (If yes, then indicate condition below).  Yes  No

OTHER COMMENTS: