PARENTAL KNOWLEDGE OF BEHAVIORAL PRINCIPLES FOLLOWING TRAINING TO ADDRESS SLEEP PROBLEMS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS: A FOLLOW-UP STUDY

by

Kylan Turner

B.Phil, University of Pittsburgh, 2006M.Ed., University of Pittsburgh, 2008

Submitted to the Graduate Faculty of

School of Education in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

University of Pittsburgh

UNIVERSITY OF PITTSBURGH

SCHOOL OF EDUCATION

This dissertation was presented

by

Kylan Turner

It was defended on

November, 15, 2012

and approved by

Christopher Lemons, PhD, Assistant Professor, Department of Instruction & Learning

Douglas Kostewicz, PhD, BCBA-D, Assistant Professor, Department of Instruction & Learning

Bernard Fabry, PhD, BCBA-D, Part-time Professor, Department of Instruction & Learning

Cynthia Johnson, PhD, BCBA-D, Associate Professor, Department of Pediatrics

Louise Kaczmarek, PhD, Associate Professor, Department of Instruction & Learning

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Sleep problems are a common occurrence among children with autism spectrum disorders (ASD). In addition to the challenges that sleep problems present for children's neurodevelopment, learning, and daytime behaviors, sleep problems in children present significant challenges for the entire family. Research studies on behavioral interventions to address sleep problems in young children have shown them to be effective. These interventions have often been combined in multi-component behavioral parent training (BPT) programs to teach parents to assess and intervene to improve children's various sleep problems. Although there is a promising evidence base emerging that demonstrates the effectiveness of BPT as a model to address sleep problems in young children with ASD, research on parents' knowledge and generalization of behavioral methods has been nearly absent in this line of inquiry. This research study evaluated maintenance and generalization of parent knowledge 6-12 months following parents' participation in a randomized controlled trial (RCT). Parents' knowledge of behavioral methods, children's sleep behaviors, parents' ratings of stress and other demographic factors (e.g., education and income) were compared between a BPT group and a psychoeducational group of the RCT. Additionally, results from a brief qualitative interview are presented to assess parents' performance in addressing children's sleep behavior. The results of this follow-up study as well as recommendations for future research will be discussed.

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PREFACE

I have had more supportive and forward-thinking mentors than any one person deserves. Immediately, I must thank both of my dissertation co-chairs. First, I need to thank Dr. Louise Kaczmarek for taking the time to really teach me how to write and for giving me critical feedback all of these years, even if it needed to sometimes be repeated. I also must thank Dr. Cynthia Johnson for teaching me to be efficient, assertive, and for providing me with so many opportunities to advance my work. I would also like to thank my remaining Dissertation Committee members for, in one way or another, teaching me to be a better clinician, researcher, and person. Thanks also must go to Diana Knoll for being such a steady and warm source of support during my entire graduate career.

Thank you, mom, for your blind faith in my ability to reach this point and for always reminding me to take advantage of every opportunity to learn. Dad, thanks for always telling me to keep my perspective balanced and to remember that this stage too would end. Thank you both for showing me through your actions and words how to work hard, behave honorably, and serve others. To my more recently acquired, honorary parents, thank you, Gail and Rich, for being strong models in leading a well-balanced work life and for always believing in me.

Robert, you have been there for every step of this journey. You have kept me going when I needed to keep going and you have helped convince me to take a break when I ran out of steam. You have done amazing things just to keep me on track, like driving me across Pennsylvania in the middle of the night after a snowstorm cancelled our flight, just so I could make it in time to a morning exam. Somehow, you have made this long, unpredictable, and arduous journey fun. Thank you for your patience, understanding, un-wavering confidence, and

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love (even on the difficult days). Thank you for always being able to make me laugh, no matter what. None of this could have happened without you.

I also must thank the Autism Center staff at Children's Hospital of Pittsburgh of UPMC, especially Emily Foldes and Erin Bailey for always making our work logistically possible. Thanks also go to the Statistical Consulting Service (SCS) in the Center for Statistics for serving as a consistent and highly accessible resource, assisting me at several points during the development of this project. None of the work that was done for this study would have been possible without the participation of the parents and children who donated their time and energy in the completion of countless assessments, visits, and interviews. And thanks also to Johanna Taylor for being an amazing partner in crime, sounding board, creative resource, and true friend all these years. Not everyone has the pleasure of working with their best friend while completing such significant milestones, and for that, I know I'm very lucky. You too have made this particular journey quite fun.

Last, I need to thank a little boy, Max, who happened to live on my street 13 years ago and changed my life. Max, you taught me what it felt like to help someone and I have never forgotten. Thanks also, for teaching me that cars don't go on boats, except in the unusual case of a ferry.

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1.0 INTRODUCTION

A large proportion of children with autism spectrum disorders (ASD) have been shown to display sleep disturbances (Hering, Epstein, Elvoy, Iancu, & Zelnik, 1999; Patzold, Richdale, & Tonge, 1998; Richdale and Prior, 1995). Sleep problems are known to impact neurological development (Bernier, Carlson, Bordeleau, & Carrier, 2010; Carskadon, Harvey, & Dement, 1981; Mirmiran & Vansomeren, 1993; Kurth et al., 2010; Randazzo, Muehlbach, Schweitzer, & Walsh, 1998), learning (Stickgold, Hobson, Fosse, & Fosse, 2001; Frank & Benington, 2006), and behavior (Dahl, 1996; Horne, 1993) in children. Reported sleep problems in children with ASD include difficulty initiating and maintaining sleep (Richdale, 1999), early morning wakings, bedtime resistance, excessive daytime sleeping (Friedman & Luiselli, 2008), night terrors, nightmares, repetitive rhythmic behaviors, and sleep disordered breathing (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008).

The effect of children's sleep disturbance on families is significant. Increased disturbance of their own sleep (Couturier et al., 2005), elevated stress (Wiggs & Stores, 2001), anxiety, and depression (Chu & Richdale, 2009) have all been shown to occur in parents who care for children with co-occurring sleep disturbances. Behavioral interventions have proven to be efficacious in the treatment of sleep disturbances in typically developing children (Mindell, 1999). In particular, standard extinction (Durand & Mindell, 1990; Ferber, 1996; Mindell & Durand, 1993; Pritchard & Appleton, 1988; Williams, 1958), graduated extinction (Adams & Rickert, 1989; Lawton, France, & Blampied, 1991; Minde, Faucon, & Falkner, 1994; Rolider & Van Houten, 1984; Van Houten & Rolider, 1984), bedtime routines (Adams & Rickert, 1989; Galbreith, Pritchard, & Hewitt, 1993; Weir & Dinnick, 1988), social stories (Burke, Kuhn &

Peterson, 2004), scheduled awakenings (Johnson, Bradley-Johnson, & Stack, 1981; Johnson & Lerner, 1985; McGarr & Hovell, 1980; Rickert & Johnson, 1988), and parent training programs (Adair, Zuckerman, Bauchner, Philipp, & Levenson, 1992; Kerr, Jowett, & Smith 1996; Wolfson, Lacks, & Futterman, 1992) have all shown at least promising results in addressing sleep disturbances in typically developing children. Although much of the current literature indicates the need for studies incorporating larger samples and more controlled trials (Schreck, 2001), evidence in support of extinction procedures, scheduled awakenings (Durand, 2002), positive routines (Durand & Christodulu, 2004; Christodulu & Durand, 2004), social stories (Moore, 2004), and multi-component parent training (Montgomery, Stores, & Wiggs, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005; Wiggs & Stores, 1998; Wiggs & Stores, 1999) have all demonstrated promise for use with children with developmental disabilities.

The behavioral parent training (BPT) model of service delivery has been used in practice with parents of children with ASD for many years and has substantial research to support its effectiveness. Despite this widely accepted practice in the ASD intervention field, there have only been a small number of randomized controlled trials evaluating parent training (Aman et al., 2009; Dawson et al., 2010; Drew et al., 2002; Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998; Ozonoff & Cathcart, 1998; Smith, Groen, & Wynn, 2000; Sofronoff, Leslie, & Brown, 2004; Tonge et al., 2006), and none of these have focused specifically on evaluations of parent training geared to address sleep disturbances in young children with ASD. Due to the pivotal role parents of children with ASD play in supporting their children's development and the evidence to support BPT for teaching other skills, the parent training treatment model provides potential to ameliorate sleep problems in this population. An empirically rigorous evaluation of a parent

training program employing behavioral interventions is an important next step in the treatment of sleep problems in children with ASD.

In addition to the common measures of target behaviors and social validity that are obtained within a randomized controlled trial, an additional evaluation of parents' maintenance and generalization of knowledge would be important to determine whether changes seen during parent training maintain over time (Eyberg, Edwards, Boggs, & Foote, 1998). Parents who continue to apply knowledge they were taught may be assumed to be more likely to continue to utilize methods to impact their children's sleep behavior over time. Conversely, if parents fail to maintain the knowledge they were taught, it is possible that the children's sleep behaviors may be more likely to deteriorate due to a parents' return to baseline knowledge of how to address the target behaviors and lack of application of parent skills (Webster-Stratton & Hammond, 1997). It was the purpose of this dissertation to examine parents' performance on a knowledge-based assessment following a behaviorally-based parent training sleep program as it related to children's current sleep behavior and parents' current ratings of stress. A follow-up evaluation of a randomized controlled trial assists in providing empirical evidence on the long term efficacy of the overall training program.

1.1 BACKGROUND OF THE STUDY

1.1.1 Definition of the Terms

The definition of what constitutes a sleep problem varies by a child's age, as sleep behavior changes over the course of development. Adults are often able to reliably report their own sleep problems, but children rarely identify or complain of sleep disturbances independently. Therefore, family members often identify children's sleep problems as they are frequently affected by children's behavior at night (Mindell & Owens, 2009).

Sleep behavior is governed by both internal and external factors. Internal factors include the biochemical, physiological or behavioral processes of the circadian rhythm, a naturally occurring, oscillating cycle that occurs over the course of about 24 hours (Loros & Dunlap, 2001). External factors play a large role in the establishment and maintenance of the synchronization of the internal circadian rhythm with the light-dark cycle; this process of entrainment leads to a predictable sleep-wake cycle as children develop. This rhythm is also guided by other influences including social activity and feeding schedules. It is clear that the facilitation of a consistent schedule by caregivers can aid in the development of appropriate sleep behavior.

1.1.2 Assessment Methods

Sleep behaviors are often assessed using multiple reporting and measurement procedures. Questionnaires specifically designed to probe for sleep disturbances may be completed either by the individual reporting sleep problems or a caregiver reporting children's sleep problems. A variety of questionnaires are available for the assessment of sleep in young children. Sleep diaries are also often used to obtain a sample of sleep behavior over a period of time and usually require an individual to record basic sleep behaviors, such as bedtime, wake time, and number of night wakings over the course of several days.

Objective measures of sleep behavior include polysomnography (PSG) and actigraphy. PSG is conducted in laboratory settings and involves obtaining recordings of biophysiologic changes (eye, brain, skeletal and heart activity) during sleep (Bruni et al., 2007). An actigraph is much less invasive than PSG and measures physical activity as a proxy for sleep / wake states. Actigraphs, watch-like devices, are generally placed on the subject's wrist of their non-dominant

hand, and, with the use of software employing specific algorithms to assess sleep, data on particular sleep behavior is collected (Sitnick, Goodlin-Jones, & Anders, 2008).

1.1.3 Sleep Problems in Children with ASD

1.1.3.1 Prevalence of sleep problems. Although sleep problems are not included in the diagnostic criteria or core features of ASD, a large percentage, approximately 44-83% of children with autism between the ages of three and fifteen years old experience some type of sleep problem (Krakowiak et al., 2008; Richdale and Prior, 1995; Richdale & Schreck, 2009). Children with ASD who were younger than eight years of age often showed more marked sleep impairment than older children (Richdale & Prior, 1995).

Although parents are certainly perceived to possess the most knowledge about their children's sleep behavior, the accuracy of parental perception of children's sleep behavior has been questioned (Schreck, & Mulick, 2000). Sleep problems in children with ASD have been documented largely via parent report and, in some cases more objective measures of sleep behavior such as sleep diaries and actigraphy. When both methods have been used together, parent reports of children's sleep disturbances have at times under- (Honomichl, Goodlin-Jones, Burnham, Gaylor, & Anders, 2002) or over-estimated (Hering et al., 1999) the actual occurrence of these behaviors in children with ASD.

There has been speculation about the role of intellectual functioning in the development of sleep disturbance in children with ASD. Richdale and Prior (1995) evaluated sleep behavior in children with ASD with and without intellectual disability as well as typical controls. The results indicated that there was no difference in the rate of sleep problems in higher- and lowerfunctioning children with ASD, but that the occurrence of sleep problems was higher in both ASD groups than the typical control group. Patzold et al. (1998) also failed to find any

significant correlations between sleep disturbances and IQ when they evaluated the sleep behaviors in children with autism, Asperger disorder and typical controls. Results showed significant differences between the ASD groups and the control group in the reporting of sleep problems. This evidence suggests that children who have ASD but not intellectual disability still have similar sleep patterns (or problems) as children who have ASD and intellectual disability. Sleep problems may be occurring with the ASD diagnosis rather than with the presence of an intellectual disability.

1.1.3.2 Types of sleep problems. Although clinicians have yet to reach agreement on the definition of many sleep disorders, it is common for sleep problems to be classified into two categories: problems initiating or maintaining sleep (dyssomnias) or disruptions in the transitions between sleep stages and partial arousals (parasomnias) (Schreck, 2001). Despite the American Sleep Disorders Association's (1990) documentation of specific criteria for these categories of sleep disorders, the literature on sleep problems for children with ASD has not used these criteria and instead have most frequently used broad definitions of dyssomnias and rarely focused on the reporting of specific parasomnias (Schreck, 2001). Therefore, the most commonly identified sleep problems in the literature of children with ASD include night waking, early morning waking, and bedtime disruptions (e.g., bedtime resistance and tantrums leading to delayed sleep onset) (Richdale, 1999; Schreck, 2001).

1.1.4 Effects of Sleep Problems on the Child's Family

A small number of studies have investigated the adverse effects on caregivers of children with severe sleep problems and ASD (Couturier et al., 2005; Hoffman et al., 2008; Wiggs & Stores, 2001; Williams, Sears, & Allard, 2006). Elevated stress levels in addition to the common effects of sleep disruption on adults (e.g., depression and anxiety) were found to occur in the majority of

families with children with developmental disabilities and sleep disturbances (Chu & Richdale, 2009). In one study, when sleep disturbances were adequately treated in children with severe intellectual disability, a decrease in maternal stress resulted (Wiggs & Stores, 2001).

1.1.5 Treatment of Sleep Disturbances as a Focus of Early Intervention Services

Early intervention (EI) services have long addressed the unique and complex needs that young children with disabilities often present. EI services are frequently delivered in children's homes (from birth to three years) or in children's preschools (three to five years of age). These services are intended to be collaborative and family-centered and often address a wide-range of developmental issues. Given that children with ASD are often recipients of early intervention services and that they often present with sleep disturbances, it is critically important for early intervention professionals to be capable of assisting parents to address these disturbances. After all, if a young child is getting inadequate sleep, optimal progress in EI will not be realized.

1.2 STATEMENT OF THE PROBLEM

This study assessed whether a behavioral parent training (BPT) program results in a superior performance of a knowledge-based assessment of behavioral methods and procedures to address children's sleep problems than that of a group of parents who did not receive BPT 6-12 months following the training. Determining whether this knowledge has been maintained and whether it is related to children's sleep behavior, parents' ratings of stress, parents' education and income as well as parents' qualitative statements about their perspective on the value of the intervention assists in identifying the role that parent's application of knowledge may play in BPT programs.

The purpose of this study was to evaluate parents' knowledge and generalization of behavioral principles, children's sleep behavior, parents' ratings of stress, and qualitative statements about perspectives on the program 6-12 months following five sessions of either a

multi-component behavioral parent training (BPT) program to address sleep problems or a psycho-educational (PE) program.

This study was designed to answer the following research questions: a) What are parents' ratings on maintenance variables (i.e., children's sleep behaviors and parents' reported stress) at a 6-12 month follow-up? b) What are participants' scores on the Knowledge Assessment 6-12 months following participation in BPT or PE? c) Are there relationships between maintenance and demographic variables and participants' scores on the Knowledge Assessment at follow-up? d) What do parents report in a qualitative interview inquiring about their experiences participating in BPT or PE 6-12 months later?

CHAPTER 2. LITERATURE REVIEW

Autism spectrum disorders (ASD) include Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD NOS) and Asperger Disorder. ASDs are complex developmental disorders that are most often indicated by impairments in the areas of social and communication development, as well as the presence of restricted repetitive stereotyped patterns of behavior, interests or activities (American Psychiatric Association, 2000). Although individuals with Asperger Disorder have average to superior intellectual functioning, the majority of individuals with Autistic Disorder have intellectual disability (Fombonne, 2009). This literature review begins with a brief discussion of hypotheses on the etiology of sleep problems in children with ASD and goes on to review studies of behavioral interventions to address sleep problems in typically developing children because of the limited number of studies focused on children with ASD alone. Within the review of interventions, a major focus is on the provision of behavioral interventions to address sleep problems and BPT as a mechanism of intervention delivery.

2.1 ETIOLOGY OF SLEEP PROBLEMS IN ASD

At least four potential explanations for sleep problems in children with ASD have been proposed in the literature. The first hypothesized cause for sleep problems involves the common deficits children with ASD display in reading environmental cues (Couturier et al., 2005; Richdale, 1999). It has been suggested that the sleep/wake cycle, as a circadian rhythm, requires entrainment (synchronization of the sleep-wake cycle with the light-dark cycle) that is greatly facilitated by cues in the environment signaling marking points of this cycle. Examples of these cues include: darkness signaling bedtime or daylight as a signal to awaken.

The second hypothesis focuses on the possibility that the often co-occurring arousal and anxiety symptoms in children with ASD (Volkmar & Cohen, 1985; White & White, 1987) may play a role in the sleep problems commonly seen in this population. Anxiety and fears have clearly been associated with sleep problems in children without ASD (Ferber, 1996; Stores, 1992; Wagner, 1991).

The third hypothesis suggests that the hyper- or hypo-arousal (over or under responsiveness to sensory stimuli, respectively), which children with ASD have long been reported to demonstrate, may impact their ability to achieve and maintain sleep (Richdale, 1999). More research to this end is clearly necessary.

A fourth potential explanation involves neurochemical differences in children's brains which impact biochemistry and neurotransmitters (Stores & Wiggs, 1998). Specifically, the production of the hormone, melatonin, has been documented to play a major role in the control of sleep (Pandi-Perumal, Trakht, Srinivasan, Spence et al., 2008) and may be produced in lower amounts in children with ASD (Richdale, 1999; Stores & Wiggs, 1998).

2.2 BEHAVIORAL INTERVENTIONS USED TO ADDRESS SLEEP PROBLEMS IN CHILDREN

Interventions for sleep disturbance in typically developing young children have primarily focused on behavioral interventions and parent education, placing parents in the role of intervention delivery agents for specific protocols (Williams, Sears, & Allard, 2006). Several researchers have put forth a remarkable set of empirical studies evaluating interventions that utilized the principles and procedures of applied behavior analysis (ABA) for the treatment of sleep disturbances among typically developing young children (infants, toddlers, and preschoolers) such as bedtime problems and night wakings. Interventions have varied from 2 to

8 weeks in duration (Mindell, 1999). There are a number of behavioral procedures that have been shown to positively impact sleep problems, including standard and graduated extinction procedures, the use of positive routines, scheduled awakenings, faded bedtimes, and stimulus control procedures.

Recently, two literature reviews were published evaluating the literature on behavioral interventions to address sleep problems in children with ASD (Turner & Johnson, 2012; Vriend Corkum, Moon, & Smith, 2011). Both of these reviews utilized standards criteria for the evaluation of evidence supporting specific intervention literature bases. Vriend and colleagues (2011) applied Chambless and Hollon's (1998) criteria to place evidence for particular interventions into one of three categories: 1) well established; 2) probably efficacious; and 3) possibly efficacious. Vriend and colleagues (2011) concluded that none of the interventions to address sleep problems fit the evidence criteria to be deemed *well established* or even *probably* efficacious according to these criteria. However, the evidence base evaluating standard extinction and scheduled awakenings met criteria to be deemed possibly efficacious because both evidence bases showed improved sleep problems in more than three participants without conflicting evidence (Vriend Corkum, Moon, & Smith, 2011). Although positive outcomes were reported, there was insufficient evidence (too few well-controlled studies with large samples) examining graduated extinction, faded bedtime, and stimulus fading to place these intervention evidence bases into one of Chambless and Hollon's (1998) criteria categories.

Turner and Johnson's (2012) review of behavioral interventions for children with ASD derived similar results on the same set of studies as Vriend and colleagues (2011), but applied different standards criteria. This review used the standards criteria from the National Autism Center's National Standards Project (NSP; 2009) due to its recommendation for use as a tool to

evaluate intervention studies specifically with children with ASD. As opposed to the three categories used to evaluate the evidence base in Chambless and Hollon's (1998) criteria, the NSP presents four categories for evidence. Turner and Johnson (2012) independently reviewed and assigned a Scientific Merit Rating Scale score for each study. These studies were then placed into one of two intervention categories (antecedent- or consequence-based) depending on whether the intervention was one intended to prevent sleep problems or occur after sleep problems occurred. Then, the ratings were compiled and evidence for both types of intervention were categorized as *established*, *emerging*, *unestablished*, or *ineffective/harmful*. Both the antecedent-based (bedtime fading, sleep restriction, and scheduled awakenings) and consequence-based (standard and graduated extinction) intervention evidence fit the criteria for *emerging* evidence according to the NSP (Turner & Johnson, 2012).

It is important to note that Vriend and colleagues (2011) applied evidence criteria to individual interventions, whereas Turner and Johnson (2012) collapsed interventions into broader categories prior to applying evidence criteria, and therefore concluded higher evidence strength ratings. Arguably, the use of broader intervention categories when evaluating this body of evidence is more appropriate due to the common, recommended practice of employing multiple interventions at once rather than the use of specific interventions in isolation. Nevertheless, both reviews concluded the need for more research on behavioral interventions to address sleep problems in children with ASD that includes larger samples and well-controlled designs.

For the current study, a search was carried out to identify all relevant empirical articles. Google Scholar, PubMed, PsychInfo, and Ovid computer searches were conducted using one of the following keywords from each of these categories: (a) child, children, pediatric, toddler, and

preschool; (b) typical, autism, autism spectrum disorder, mental retardation, and learning disability; (c) sleep, sleep problem, sleep disorder, sleep disturbance, sleeplessness, insomnia, night awakening, night waking, bedtime problems, bedtime resistance, and bedtime refusal; (d) treatment, intervention, parent training, and approach. No restrictions were placed on publication date. The results are described below, organized by intervention categories.

2.2.1 Bedtime Routines / Schedules

Often, the most salient feature of a behavioral package to address sleep disturbance in young children is the incorporation of a structured bedtime routine to address bedtime resistance or problems with sleep latency (a delay in falling asleep once in bed). Bedtime routines largely consist of instituting a clear and consistent bedtime routine, incorporating calming and preferred activities, and presenting positive reinforcement for compliance. Bedtime routines are considered to be an antecedent intervention due to their function to set the stage for sleep onset and to offset the need for a child to engage in a challenging behavior at nighttime.

Studies evaluating the use of bedtime routines have been conducted with typically developing children (Adams & Rickert, 1989; Burke, Kuhn, & Peterson, 2004; Galbreith et al., 1993), children with disabilities (Milan, Mitchell, Berger, & Pierson, 1981), and in three studies with children with ASD (Christodulu & Durand, 2004; Durand & Christodulu, 2004; Wolf, Risley, & Mees, 1964). As a whole, this literature base has included single subject designs (Burke et al., 2004; Christodulu & Durand, 2004; Durand & Christodulu, 2004; Milan, Mitchell, Berger, & Pierson, 1981; Wolf, Risley, & Mees, 1964) as well as a randomized controlled trial (Adams & Rickert, 1989). Bedtime routine protocols have been used to effectively target bedtime refusal (Adams & Rickert, 1989; Burke et al., 2004; Christodulu & Durand, 2004; Christodulu, 2004; Hilan, Mitchell, Berger, & Pierson, 1981; Wolf, Risley, Burke et al., 2004; Christodulu & Durand, 2004; Christodulu & D

Moore, 2004), night wakings (Christodulu & Durand, 2004; Galbreith et al., 1993; Wolf, Risley, & Mees, 1964), difficulty initiating sleep (Durand & Christodulu, 2004), and also children sleeping in places other than their bed or with a parent (Burke et al., 2004; Moore, 2004). Follow-up measures were obtained for almost all of the studies on bedtime routines and indicated maintenance of these treatment changes at time-points of 1 month to 2 years following treatment (Adams & Rickert, 1989; Burke et al., 2004; Christodulu & Durand, 2004; Milan, Mitchell, Berger, & Pierson, 1981). The results of the studies evaluating bedtime routines demonstrated the efficacy of a cost-effective and practical component to address a wide range of sleep problems in children with and without developmental disabilities. Given the relative ease of this intervention and high ratings of acceptability by parents, bedtime routines have become a preferred method in the initial treatment of sleep disturbances in children.

Although only three studies have been published that evaluated the use of bedtime routines / schedules with children with ASD, the results of these three studies demonstrated the effectiveness of this antecedent-based intervention specifically with this group of children (Christodulu & Durand, 2004; Durand & Christodulu, 2004; Wolf, Risley, & Mees, 1964). In both of their studies, Christodulu and Durand (2004) taught parents to implement a bedtime routine in their homes, whereas Wolf and colleagues (1964) conducted the intervention initially on an inpatient unit and gradually transferred the intervention to delivery in the child's home by his parents. These studies provide evidence for a straightforward and efficient approach to minimize or prevent behavioral problems associated with sleep onset in children with ASD.

2.2.2 Standard Extinction

The efficacy of standard extinction procedures to address bedtime problems and night wakings in typically developing children has been investigated by several researchers either as a stand-alone

treatment (Williams, 1958) or as a part of a treatment package (Durand & Mindell, 1990; Ferber, 1985; Hiscock & Wake, 2002; Mindell & Durand, 1993; Pritchard & Appleton, 1988; Sadeh, 1994), and has been demonstrated over the course of these investigations to be an intervention with a well-established evidence base (Mindell, 1999). Standard extinction to address sleep behavior consists of an adult consistently withholding reinforcement following undesired behaviors when the child is meant to be sleeping. For example, if a child engaged in crying episodes in the night to obtain adult attention, a standard extinction procedure would consist of the adult withdrawing attention from (ignoring) the child's behavior until the behavior were to cease (Mindell, 1999).

Standard extinction has primarily been evaluated with children who are typically developing, although Wolf and colleagues (1964) evaluated standard extinction in conjunction with a bedtime routine and mild punishment procedure with one child with ASD. Several of these studies included small sample sizes to address night wakings (Chadez & Nurius, 1987; France & Hudson, 1990; Wolf, Risley, & Mees, 1964), severe tantrums (Wolf, Risley, & Mees, 1964) or bedtime refusal (Rapoff, Christopherson, Rapoff, 1982; Williams, 1958). However, a few studies have included moderate to large sample sizes to address night wakings (Rickert & Johnson, 1988; Seymour, Bayfield, & During, 1983), or both night wakings and bedtime refusal (Seymour, Brock, During, & Poole, 1989). Williams' (1958) study was the first to document the use of extinction in a publication of a case history. Studies on standard extinction have employed concurrent multiple baseline (Rapoff et al., 1982), non-concurrent multiple baseline (France & Hudson, 1990), reversal designs (Chadez & Nurius, 1987), and a case study (Wolf, Risley, & Mees, 1964). Other studies have contributed to the rigor of this literature base by including large samples in a within-subject design (Seymour, Bayfield, & During, 1983) and

randomized trials with comparison groups (Rickert & Johnson, 1988; Seymour, Brock, During, & Poole, 1989).

All of the studies evaluating standard extinction have employed similar protocols that consisted of putting the child to bed and not returning to the child's room. Each of these protocols stated that if the child got out of bed, parents should quietly place the child back in bed. In addition to this extinction protocol, two older studies included a mild punishment that consisted of physically "swatting" the child before the parents placed the child back in bed (Rapoff et al., 1982; Wolf, Risley, & Mees, 1964).

The majority of these studies used sleep diary recordings (Rickert & Johnson, 1988; Williams, 1958), and parent-completed questionnaires or reports (Chadez & Nurius, 1987; France & Hudson, 1990; Seymour, Bayfield, & During, 1983; Seymour, Brock, During, & Poole, 1989), and direct observation (Wolf, Risley, & Mees, 1964). Although these measures were helpful in determining bed and wake times, sleep diaries may not detect all night wakings or times when the child happens to be awake but not disturbing parents' sleep. More objective measures of these variables included audiotape recordings (Rapoff et al., 1982), daily telephone checks and a voice-activated relay (VAR) device that recorded night wakings using a switch-mat device (France & Hudson, 1990) which greatly enhanced reliability. In an effort to verify procedural fidelity in the home, France and Hudson (1990) made phone calls to participants and Adams and Rickert (1989) asked the children's fathers or family friends to conduct reliability checks in the home. In the only study with a child with autism, Wolf and colleagues (1964) conducted the standard extinction protocol in an inpatient unit initially, thus having the advantage of on-site staff members to carry out the procedure and record data. Later, researchers

taught parents to complete the protocol at home once night wakings ceased in the clinic environment.

Overall, the results reported in the literature on standard extinction indicated swift reductions in the target behaviors of bedtime refusal and night wakings. Specifically, the literature showed that extinction was effective at reducing the duration of crying at bedtime (Rapoff et al., 1982; Seymour, Brock, During, & Poole, 1989; Williams, 1958; Wolf, Risley, & Mees, 1964) and frequency of night waking (France & Hudson 1990; Seymour, Bayfield, & During, 1983; Seymour, Brock, During, & Poole, 1989; Wolf, Risley, & Mees, 1964). Chadez and Nurius employed cognitive restructuring with the parents of the subject in their study and found that extinction was only effective during the conditions when this additional procedure was used. Of the studies that included a comparison group, extinction was shown to result in reductions of target sleep problems faster than scheduled awakening (Rickert & Johnson, 1988). Standard extinction was equally effective when training was delivered via written instruction or with therapist guided instruction (Seymour, Brock, During, & Poole, 1989). Follow-up data were collected for all studies with time-points varying from 47 days to 2 years post-treatment and demonstrated maintenance of treatment change (Chadez & Nurius, 1987; France & Hudson, 1990; Rapoff, 1982; Rickert & Johnson, 1988; Seymour, Bayfield, & During, 1983; Seymour, Brock, During, & Poole, 1989; Williams, 1958; Wolf, Risley, & Mees, 1964).

It is important to note that although standard extinction produced positive results in addressing the target behaviors across all of the studies, Seymour et al. (1983) reported attrition from 15 of their 208 participants. The attrition rate in this study could have been attributed to parents' potential lack of acceptability or adherence in completing the protocol due to the challenges associated with ignoring their children's night wakings. Parent adherence has been

reported to be low in other studies (Adams & Rickert, 1989; Mindell, 1999). (See Figure 1 in Appendix A)

A commonly cited practical weakness of extinction is the extinction burst, which is a sudden and dramatic increase in the targeted behavior before a consistent decrease is observed (Lerman & Iwata, 1995). In the treatment of sleep disturbances, extinction bursts are often responsible for adults violating the extinction procedure and going to check on the child (providing attention), thus weakening the strength of the recently acquired contingency. Many studies had previously acknowledged the challenges associated with standard extinction and had even obtained data indicating variable rates of acceptability from parents using the procedure due to the difficult task of ignoring their children's often intense crying (Ferber, 1985; Schreck, 2001). Thoughtful consideration of how best to offset these temporary increases in undesirable behavior has resulted in stronger support for modifications to the standard extinction protocol, such as graduated extinction.

2.2.3 Graduated Extinction

Whereas when using standard extinction a parent would place a child's nighttime behaviors on extinction in one swift move, graduated extinction involves the same process occurring in gradual stages over time (Adams & Rickert, 1989; Lawton, France, & Blampied, 1991; Minde, Faucon, & Falkner, 1994; Rolider & Van Houten, 1984; Van Houten & Rolider, 1984). For instance, instead of fully ignoring each of the child's undesired behaviors from the start of the procedure, in graduated extinction, the parent enters the child's bedroom to ensure the child's safety on a regular schedule (i.e., every 10 minutes) and interacts with the child minimally. The interval for when this attention is provided gradually increases over time (i.e., from every 10 minutes to every 20, etc.). Hence, the adult's attention is not contingent on the child's behavior,

but rather, on a pre-determined schedule. This procedure is repeated until the child falls asleep and when the child wakes in the night and displays attention-seeking behaviors (Minde, Faucon, & Falkner et al., 1994).

A large number of studies have evaluated the use of graduated extinction with typically developing children and one study evaluated graduated extinction as a stand-alone treatment with two children with ASD (Durand, Gernert-Dott, & Mapstone, 1996). Several studies have used multiple baseline designs with small sample sizes (Durand, Gernert-Dott, & Mapstone, 1996; Durand & Mindell, 1990; Lawton, France, & Blampied, 1991; Mindell & Durand, 1993; Rolider & Van Houten, 1984), randomized group designs (Adams & Rickert, 1989; Sadeh, 1994) or quasi control groups (Pritchard & Appleton, 1988).

Similar to the standard extinction protocols, the majority of studies evaluating graduated extinction targeted bedtime refusal (Adams & Rickert, 1989; Durand, Gernert-Dott, & Mapstone, 1996; Rolider & Van Houten, 1984), night waking (Mindell & Durand, 1993; Sadeh, 1994), or both (Durand & Mindell, 1990; Lawton, France, & Blampied, 1991; Pritchard & Appleton, 1988). All of the studies utilized a standard protocol for graduated extinction using an interval for checking on the child based on the parents' wishes and this initial interval was increased gradually over time (Adams & Rickert, 1989; Durand, Gernert-Dott, & Mapstone, 1996; Durand & Mindell, 1990; Lawton, France, & Blampied, 1991; Mindell & Durand, 1993; Rolider & Van Houten, 1984; Sadeh, 1994). In Pritchard and Appleton's (1988) and Durand and colleagues' (1996) studies, a consistent bedtime routine was also incorporated into the protocol.

Each of the studies evaluating graduated extinction utilized sleep diaries as a measure of target behaviors (Adams & Rickert, 1989; Rolider & Van Houten, 1984; Durand, Gernert-Dott, & Mapstone, 1996; Durand & Mindell, 1990; Lawton, France, & Blampied, 1991; Mindell &

Durand, 1993; Pritchard & Appleton, 1988; Sadeh, 1994). Studies by Adams and Rickert (1989) and Lawton, France, and Blampied (1991) also used reliability checks wherein a third party (e.g., the child's father or a family friend) independently recorded the same sleep diary information. In studies by Durand and Mindell (1990) and Mindell and Durand (1993) researchers videotaped the home environment. Using third party observers and video technology enhanced the reliability of the dependent measures of sleep behavior and further documented procedural fidelity to rigorously evaluate the treatment being given directly to the child.

Graduated extinction was shown to be effective at reducing bedtime problems (Adams & Rickert, 1989; Durand, Gernert-Dott, & Mapstone, 1996; Rolider & Van Houten, 1984), night waking (Mindell & Durand, 1993; Sadeh, 1994), or both (Durand & Mindell, 1990; Lawton, France, & Blampied, 1991; Pritchard & Appleton, 1988). In the studies that incorporated a comparison group, graduated extinction was found to be equally effective to a parent sleeping in the child's room and not providing additional attention (Sadeh, 1994) and positive routines (Adams & Rickert, 1989). It is also important to note that parents in this latter study found the graduated extinction protocol to be more difficult to implement than the positive routine, as parents were required to continuously check on the child in the night. Each of these studies demonstrated maintenance in the reduction of target behaviors at follow-up time-points of 3 weeks to 9 months post-treatment (Adams & Rickert, 1989; Durand & Mindell, 1990; Mindell & Durand, 1993; Lawton, France, & Blampied, 1991; Pritchard & Appleton, 1988; Rolider & Van Houten, 1984; Sadeh, 1994). However, Durand and colleagues' (1996) study did not report follow-up data.

Graduated extinction was only evaluated in one study as a stand-alone treatment with children with ASD, but demonstrated reductions in sleep onset and maintenance behaviors

(Durand, Gernert-Dott, & Mapstone, 1996). This study employed a multiple baseline across subjects design with four children, two of whom had autism while the others were characterized as having developmental disability. Despite the small number of children with ASD in the sample, the results indicate promising evidence for graduated extinction as a variation of the standard extinction approach. (See Figure 2 in Appendix A)

2.2.4 Bedtime Fading

Bedtime fading is often used as an intervention to increase children's drive to sleep as well as to consolidate sleep patterns to longer periods of sleep without waking. When implementing a bedtime fading intervention, a child's bedtime is set close to when s/he is reported to naturally fall asleep. This routine is followed until a child's sleep onset occurs within a few minutes of the time they are placed in bed. After this sleep onset occurs consistently, then the bedtime is systematically moved back to an earlier time until the child is falling asleep within 20 minutes of a realistic bedtime.

Bedtime fading has been evaluated in two case studies (DeLeon, Fisher, & Marhefka, 2004; Piazza, Hagopian, Hughes, & Fisher, 1998), one case-series design (Moon, Corkum, & Smith, 2011), and a randomized controlled trial (Piazza, Fisher, & Sherer, 1997) with children with ASD. Other studies using bedtime fading protocols included a randomized trial with typically developing children (Adams & Rickert, 1989) and an additional bedtime routine component in a single subject study with children with developmental disabilities (Milan, Mitchell, Berger, & Pierson, 1981). A bedtime fading procedure was also used in conjunction with what was referred to as a response cost procedure in two studies, one including children with ASD (Moon, Corkum, & Smith, 2011) and one including children with developmental disabilities (Piazza, Fisher, & Sherer, 1997). Target behaviors in these studies included

disrupted sleep-wake schedules (i.e., early morning wakings and delayed sleep onset at night or daytime sleeping and nighttime insomnia) (Piazza, Fisher, & Sherer, 1997; Piazza et al., 1998), bedtime refusal (Adams & Rickert, 1989; Milan, Mitchell, Berger, & Pierson, 1981), night waking and self-injury (DeLeon, Fisher, & Marhefka, 2004), and sleep latency (Moon, Corkum, & Smith, 2011). The studies incorporating bedtime routines with bedtime fading consisted of providing the child with several reinforcing and calming activities before bed and also setting the schedule for these activities to fall closer to when the child would fall asleep (Adams & Rickert, 1989; Milan, Mitchell, Berger, & Pierson, 1981). The faded bedtime with response cost procedure employed by Piazza et al. (1997) and Moon et al. (2011) consisted of placing the child in bed at the time when they were most likely to fall asleep and then waking the child at a consistent pre-determined time in the morning. If the child was not asleep within 15 minutes of the time when they were placed in bed, the response cost component required that staff remove the child from bed and keep them awake for one hour completing an activity of their choice. The intent of the response cost component was to increase children's drive to sleep and to shape children's association between bedtime stimuli and sleep behavior.

Sleep diaries and reliability checks by third party observers were employed in three of the studies (Adams & Rickert, 1989; Milan et al., 1981; Moon, Corkum, & Smith, 2011) to assess the target behavior of bedtime refusal. Actigraphy, parent-completed questionnaires of sleep and daytime behaviors (Moon, Corkum, & Smith, 2011), and direct observation by parents (DeLeon, Fisher, & Marhefka; 2004; Piazza et al., 1998) were also used to measure sleep behavior. Results of these studies indicated rapid and effective reduction in target behaviors (Adams & Rickert, 1989; DeLeon, Fisher, & Marhefka, 2004; Milan, Mitchell, Berger, & Pierson, 1981; Moon, Corkum, & Smith, 2011; Piazza et al., 1998), and participants in Adams and Rickert's

(1989) study reported that bedtime fading was easier to implement than graduated extinction. Further, in Moon and colleagues' (2011) study including children with ASD, bedtime fading and response cost resulted in small decreases in daytime challenging behaviors as reported by parents as well as parent satisfaction with results. Follow-up measures were obtained for 6 weeks to 2 years and indicated maintained improvement in these behaviors.

It is important to note that three of these studies were conducted on inpatient units where hospital staff implemented behavioral protocols (DeLeon, Fisher, & Marhefka, 2004; Piazza et al., 1998; Piazza, Fisher, & Sherer, 1997). In Piazza and colleagues' (1997) study, inpatient staff collected data using a partial interval recording system on the occurrence of disturbed and undisturbed sleep. Within Piazza et al.'s (1997) 10-day treatment, the faded bedtime and response cost group demonstrated significant reductions in disturbed sleep hours (time when the child was awake beyond the recommended amount for their age); although the bedtime scheduling group demonstrated a decrease in mean hours of disturbed sleep, this pre- and post-test difference was not statistically significant.

As opposed to other behavioral strategies discussed in this review, bedtime fading has been evaluated relatively frequently with children with ASD (DeLeon, Fisher, & Marhefka, 2004; Moon, Corkum, & Smith, 2011; Piazza, 1998; Piazza, Fisher, & Sherer, 1997). In all four studies, children's sleep behavior improved and results were maintained at follow-up. Although, at first, the prospect of delaying bedtime may seem counterproductive to the goal of increasing a children's total sleep time, for many children with ASD, the results indicate that accruing motivation to sleep by delaying bedtime is an effective solution to many types of disrupted sleep schedules children may present. Further, results of two of the studies suggest desirable results
may occur more rapidly when bedtime fading is combined with response cost (Moon, Corkum, & Smith, 2011; Piazza, Fisher, & Sherer, 1997). (See Figure 3 in Appendix A.)

2.2.5 Treatment of Sleep Association and Stimulus Control Problems

Children with ASD classically demonstrate stimulus control problems such as overselectivity (e.g., a child's insistence on only hugging one family member or only eating food out of a particular bowl) (Lovaas, Koegel, & Schreibman, 1979). In the context of sleep disturbances, faulty stimulus control appears in the form of sleep association problems. The association between stimuli meant to evoke sleep (e.g., soft bed, pillows, blankets, quiet and dark room, etc.) may be weak or unreliable. Children with ASD may develop faulty connections between certain stimuli and sleep behavior. An example of this would be a child who has learned to fall asleep only when his mother lay next to him on a particular living room sofa while watching television. Whereas typically developing children may generalize that a soft cushion (whether it be a part of a sofa or their bed) will evoke sleep, a child with stimulus control problems may learn to associate the texture of the sofa with sleep and not be able to fall asleep without that particular stimulus (i.e., stimulus overselectivity). This faulty stimulus control is problematic not only when the child is attempting to initially fall to sleep, but also when the child wakes in the night and requires the same conditions to be met to achieve sleep once again.

Sleep restriction is a similar intervention to bedtime fading and utilizes the same principles to reach more consolidated sleep and accrue motivation to sleep, but also addresses sleep association problems more directly. Sleep restriction procedures ask parents to temporarily reduce children's sleep such that the child is in bed for only 90% of (10% less than) the total amount of time they usually sleep. Calculations of this total sleep time are determined using data from a carefully recorded sleep diary obtained prior to the intervention. Sleep restriction is

achieved by either delaying the onset of sleep or waking the child early in the morning and keeping them awake. In essence, the goals of this intervention are to reduce the amount of time the child is in their bed while awake and consequently, develop stronger associations, or stimulus control, between the bedroom stimuli and sleep. Additionally, as children's sleep is restricted, the motivation to achieve sleep increases. Once children begin to engage in more consolidated sleep with fewer problem behaviors at bedtime, the sleep restriction is faded to a schedule which better resembles what is recommended for young children.

Often, concurrently with sleep restriction protocols, a stimulus fading procedure may be used to slowly modify the stimuli a child is exposed to in order to broaden or replace elements of the environment which evoke sleep behavior. An example goal of stimulus fading might be to have a child sleep independently without requiring a parent to sleep in their bed. A stimulus fading procedure might include providing a child with a large pillow to cuddle at night and having the parent systematically distance themselves from the child over the course of several nights until the parent is no longer in the room when the child falls asleep.

Christodulu and Durand conducted two single subject design studies evaluating sleep restriction in 2004. The first study involved three children with developmental disabilities and one child with ASD (Christodulu & Durand, 2004, whereas the second study included one child with developmental deficits and one child with ASD (Durand & Christodulu, 2004). Howlin (1984) also conducted a case study of a child with ASD to address sleep association problems using a stimulus fading approach wherein the parent gradually and systematically positioned herself further away from the child each night. Target behaviors such as bedtime refusal, night waking and sleep association problems were addressed in all three studies (Christodulu & Durand, 2004; Durand & Christodulu, 2004; Howlin, 1984), while Durand and Christodulu

(2004) also addressed sleepwalking and sleep terrors in participants. Both Christodulu and Durand's (2004) studies utilized sleep diaries and parent-report questionnaires of children's sleep behavior whereas Howlin (1984) used data collected by direct observation from a parent. Results from all three studies indicated significant reduction in target sleep problems for all participants (Christodulu & Durand, 2004; Durand & Christodulu, 2004).

Although these studies are limited by the use of small sample sizes and do not provide follow-up data, they provide promising results for sleep restriction and stimulus fading for some children who do not respond to less intensive interventions. Of particular significance was the use of sleep restriction to address stimulus control issues such as co-sleeping with parents (Christodulu & Durand, 2004) and children sleeping in places other than their bed (Durand & Christodulu, 2004). Undoubtedly, a major challenge to the practical implementation of sleep restriction and parent adherence in future studies will be for parents to work to keep their child awake for longer periods of time throughout the night. (See Figure 4 in Appendix A)

2.2.6 Scheduled Awakenings

Scheduled awakenings have been successfully used to decrease night wakings in typically developing children (Johnson, Bradley-Johnson, & Stack, 1981; Johnson & Lerner, 1985; McGarr & Hovell, 1980; Rickert & Johnson, 1988) and sleep terrors in a sample of two children with autism also suffering from night terrors (Durand, 2002). When using this procedure, parents awaken their child approximately 15 minutes before the time when children were previously demonstrating a spontaneous night waking. When the child is awoken, parents respond to their child as if the awakening were spontaneous, or as though the parent had not intentionally woken the child. Over time, the awakenings are gradually and systematically faded to occur following longer intervals of uninterrupted sleep until the period of time when the child

is sleeping (and not waking in the night) is prolonged. The exact behavioral mechanism underlying the efficacy of this intervention is unclear (Rickert & Johnson, 1988). Clearly, considerable effort on the part of parents is required with this intervention, as they would need to physically wake their child nightly over the course of several weeks, as the children's sleep schedule is meant to be trained.

Studies on scheduled awakenings were found to be efficacious in addressing night wakings and night terrors (Durand, 2002; Johnson, Bradley-Johnson, & Stack, 1981; Johnson & Lerner, 1985; McGarr & Hovell, 1980; Rickert & Johnson, 1988) but variability in procedural adherence on the part of parents were observed. This variability in implementation was often correlated with efficacy of the intervention (Johnson, Bradley-Johnson, & Stack, 1981; Johnson & Lerner, 1985). When the intervention was followed in each of these studies, a significant decrease in night wakings was shown to occur, and conversely, when the procedure was not followed, effectiveness was not demonstrated.

Given the effort required by parents to implement scheduled awakenings with fidelity, scheduled awakenings might appear to be a less desirable intervention in the initial treatment of sleep disturbances in children with ASD. However, in the only study conducted using scheduled awakenings in children with ASD, Durand (2002) demonstrated a reduced frequency of night terrors in all three children, increased total sleep time in two of the three children in the sample, and also demonstrated parent satisfaction with results. Perhaps in spite of the great effort involved, for some families with children with ASD, the positive effects of scheduled awakenings may outweigh the effort involved.

2.2.7 Behavioral Parent Training Programs

Although many of the interventions discussed previously have been evaluated either as standalone interventions or as small packages to address particular sleep disturbances, many researchers have sought to investigate the efficiency and efficacy of multi-component behavioral parent training (BPT) programs. The development of these programs involves drawing upon the emerging efficacy of behavioral treatments to address sleep problems in young children, including: extinction, bedtime routines, bedtime fading, and treatment of sleep association problems. Wiggs and colleagues (Montgomery, Wiggs, & Stores, 2004; Wiggs & Stores, 1998; Wiggs & Stores, 1999) have conducted a few randomized controlled trials (RCT) using BPT in the treatment of sleep disturbance in children with severe learning disabilities including some children with ASD. Studies on multi-component BPT programs have included children with ASD (Moore, 2004; Montgomery, Wiggs, & Stores, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005) and Fragile X Syndrome (Weiskop, Richdale, & Matthews, 2005). This body of literature has included a case study (Moore, 2004), multiple baseline (Weiskop, Richdale, & Matthews, 2005), within subject studies (Reed et al., 2009), and a randomized controlled trial (Montgomery, Wiggs, & Stores, 2004).

These multi-component BPT programs have been used to address a broad range of sleep disturbances in participants, including bedtime refusal (Montgomery, Wiggs, & Stores, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005), night wakings (Montgomery, Wiggs, & Stores, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005; Wiggs & Stores, 1998), settling problems (Wiggs & Stores, 1998), early morning waking (Reed et al., 2009; Wiggs & Stores, 1998), and co-sleeping (Weiskop, Richdale, & Matthews, 2005). Each of these studies have provided one (Montgomery, Wiggs, & Stores, 2004), three (Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005), or six sessions (Wiggs & Stores, 1998) of face-to-face

behavioral BPT. Moore (2004) conducted a 28-day program in the participant's home with daily telephone contact after an initial assessment. Although the majority of these sessions were delivered with individual families by a parent trainer (Montgomery, Wiggs, & Stores, 2004; Weiskop, Richdale, & Matthews, 2005; Wiggs & Stores, 1998), Reed et al. (2009) evaluated the use of a group workshop with 3-5 families at a time. All of the studies employed a standardized training curriculum with opportunities for individualization. In the randomized trial by Montgomery, Wiggs, and Stores (2004), the comparison group was simply given the training booklet without face-to-face training to evaluate the necessity for therapist involvement in BPT to address sleep problems.

Assessment of sleep behavior in these studies utilized the popular convention of sleep diaries (Montgomery, Wiggs, & Stores, 2004; Weiskop, Richdale, & Matthews, 2005) and questionnaires (Moore, 2004; Reed et al., 2009; Wiggs & Stores, 1998), but also employed actigraphy to improve reliability (Reed et al., 2009; Wiggs & Stores, 1998), and a functional analysis of sleep behavior at baseline to further focus intervention efforts (Moore, 2004; Wiggs & Stores, 1998). Results for all of these studies demonstrated a reduction in targeted problematic behaviors in the majority of participants (Montgomery, Wiggs, & Stores, 2004; Moore, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005; Wiggs & Stores, 1998). An interesting finding suggesting further feasibility was the equivalent efficacy of face-to-face training and booklet-only training in the randomized trial by Montgomery, Wiggs, and Stores (2004). For the studies that obtained follow-up measures, improvements in sleep behavior were maintained at 3 to 12 months (Montgomery, Wiggs, & Stores, 2004; Weiskop, Richdale, & Matthews, 2005). Multi-component BPT is an especially appealing mechanism to address sleep problems in children with ASD. To date, four studies have been conducted using multi-component BPT that included children with ASD in their research samples (Moore, 2004; Montgomery, Wiggs, & Stores, 2004; Reed et al., 2009; Weiskop, Richdale, & Matthews, 2005). These studies included multiple components that had previously demonstrated efficacy as stand-alone treatments in pediatric populations. Given that many of the children in these particular studies displayed more than one sleep disturbance at the time of enrollment, it is likely that the provision of multiple behavioral strategies at one time assisted in a more rapid amelioration of sleep problems for children with ASD. (See Figure 5 in Appendix A.)

2.2.8 Parent Knowledge Following Behavioral Parent Training

A common goal of BPT is to provide parents with knowledge of behavioral principles to address their children's behaviors over time. Knowledge, in this case, may be considered to be the ability to *apply behavioral principles* to specific theoretical scenarios to solve a child's behavior problem. If, after a BPT program has ended, parents still apply these principles, then it may be presumed that this is because parents continue to see it as effective at addressing the issues that were the focus of the program (Kazdin, 1997). Conversely, if parents do not continue to apply this knowledge post-training, it is possible to perceive this lack of maintenance as an indication that the use of these principles were no longer perceived to be effective by the parent, or that the parent found difficulty in continuing to apply them. In this way, long-term maintenance of parents' application of behavioral principles may be an important indicator of the effectiveness of a BPT program itself as a mechanism to have parents implement changes in their children's environment to change their children's behavior. Regardless of why parents fail to continue to apply principles learned in BPT, if the knowledge is not still applied following treatment, the improvement seen in the child's behavior may fail to be maintained as well. Therefore, BPT programs that reveal long-term knowledge may also likely demonstrate that the child's behavior change has been maintained, and thus, that the training continues to be effective.

Follow-up studies investigating maintenance effects of BPT programs have been limited in terms of the outcomes that have been measured. The BPT model incorporates two levels of service delivery and both levels of delivery must be measured to fully investigate maintenance. On one level, parents are the direct recipients of intervention from parent trainers, and on a second level, children receive intervention when parents apply their BPT knowledge in the home environment. Despite the BPT model suggesting that maintenance of BPT effects may be measured in terms of parents' knowledge and delivery of intervention as well as children's ultimate behavior change, few studies have investigated the first level of the model. Instead, maintenance of BPT programs has been evaluated in terms of children's behavior only. Several studies evaluating BPT have investigated maintenance of treatment effects following parent training to address sleep disturbance in children, but none have examined maintenance of parent application of knowledge from the training or the relationship between parent and child behavior. Weiskop, Matthews, and Richdale (2001) documented successful maintenance of one child's improved sleep association and sleep latency problems at 3- and 12-month follow-up time-points but did not present data on parent's implementation of intervention, assessments of parent knowledge or application following parent training. Parent report of children's sleep behavior was also used in Weiskop, Richdale and Matthews' (2005) study of 13 children with ASD or Fragile X Syndrome at 3- and 12-month follow-up periods, but no other measures were reported to evaluate parent knowledge or application of principles.

Although maintenance of children's sleep behavior was evaluated for previous small BPT sleep programs, there has only been one study showing maintenance data for a BPT sleep program within a RCT, yet this study was not specifically focused on children with ASD. In this RCT, Montgomery et al. (2004) delivered a BPT program to address sleep problems in 66 children with intellectual disability. The RCT consisted of a face-to-face BPT group, a group that received a booklet containing the BPT information, and a waitlist control group that did not receive BPT. Parents recorded a week-long sleep diary to demonstrate maintenance of children's improved sleep six months after intervention. Although this study presented data on maintenance following a BPT within a RCT design, it only reported children's sleep behavior and not information on parents' skills or knowledge at follow-up. Additionally, there have not been any studies specifically evaluating parents' knowledge or application of behavioral methods or procedures via assessment or direct observation following parent training to address sleep problems.

Historically, maintenance and long term effects of parent training have been deduced from evidence of children's behavior following intervention only and not parents' behavior as well. Therefore, in order to adequately capture the efficacy of BPT on both levels it is necessary to determine the role that parents' application of knowledge of behavioral principles plays in children's long term maintenance of behavior change. Additionally, it is important to compare parents' application of knowledge as indicated by performance on a knowledge-based assessment 6-12 months following BPT with the skills shown from parents who have *not received* BPT. This final comparison aids in measuring the impact a BPT program has in training parents in behavioral methods and procedures. A RCT design lends itself well to such an empirical comparison.

2.2.9 Parent Knowledge of Behavioral Methods and Procedures

A major component to any BPT program involves didactic instruction in order for parents to acquire information and learn methods and procedures to address children's behavior. Although the demonstration of one's knowledge of particular concepts does not imply one's ability to use interventions effectively, the ability to apply knowledge to plan solutions to children's behavior problems is a precursor to executing the actual skills to solve them. Consequently, it is important to measure knowledge gained by those who have engaged in didactic behavioral instruction and training. Such measurements have followed both parent training and staff training studies. Although there are very few studies focused on parental acquisition of behavioral principles, there are several studies focused on staff acquisition of this knowledge. It is therefore necessary to examine that literature.

An assessment of knowledge of behavioral methods was developed to measure whether direct care staff members of an inpatient mental health program for children and adolescents may be taught interventions to address patients' behavior (St. Lawrence, Hansen, & Steele, 1985). St. Lawrence et al. (1985) provided direct care staff with an in-service training on the use of behavioral methods and procedures for intervention. Staff knowledge was assessed using 35 multiple choice items presenting common scenarios seen in the inpatient unit. Items on this assessment were adapted from the 50-item Knowledge of Behavioral Principles as Applied to Children (KBPAC; O'Dell, Tarler-Benlolo, & Flynn, 1979) and the Pain Assessment Questionnaire (PAQ; Sanders & Webster, 1982).

The inventory used by St. Lawrence et al. (1985) was administered to a total of 69 participants (23 inpatient staff, 23 behavioral psychology graduate students, 23 law students with no knowledge of behavioral principles) to assess psychometric properties of the instrument.

Internal consistency was determined to be good, ranging from .32 to .97 (M = 0.69) and the questionnaire showed strong test-retest reliability, r = 0.90 (p < .0001). Further, a content validity analysis showed the instrument's ability to discriminate between the individuals' levels of training across the three participant groups. Graduate students trained in behavioral methods scored highest with an average score of 87.2%, while the inpatient staff scored closely with an average of 55.2% with the law student group scoring an average of 52.3%. After the psychometric properties of the instrument were determined to be adequate, seven novel inpatient staff members were administered the questionnaire and then provided eight sessions of in-service training on behavioral methods and procedures. Following the in-service training, the inpatient staff members were re-administered the questionnaire and these results were compared with seven untrained and newly hired inpatient staff members. Following the eight sessions of inservice training, inpatient staff members improved from an average score of 59.5% to 71.0%. Additionally, untrained and newly hired staff members were shown to be equivalent to the pretraining scores of the inpatient staff average score of 50.1%. This indicates that the questionnaire was able to discriminate between the groups that received training and an equivalent group that did not. Despite presenting data on the knowledge that staff members showed before and after training, this study did not present data on behavioral outcomes of the patients being cared for by the staff members.

Assessment of parent knowledge of behavioral principles has only been conducted in one parent training study. Parent knowledge was assessed before and after a group parent training program to teach parents of children with ASD naturalistic behavioral and developmental approaches to increase social and communication skills (Ingersoll & Dvortcsak, 2006). Ingersoll and Dvortcsak's (2006) knowledge assessment consisted of a 10 question multiple-choice quiz.

This quiz provided parents with brief vignettes describing parent and child interactions and response options consisted of ways to increase children's social engagement and/or communication in each scenario. Parent knowledge was shown to improve from an average pre-training score of 29% to an average post-training score of 75% for the nine parents in the study. Although Ingersoll and Dvortcsak (2006) collected data on parent knowledge, the possible relationship between parent knowledge and children's outcomes was not discussed.

2.2.10 Parent Generalization of Knowledge of Behavioral Methods and Procedures

In addition to attempting to provide parents with stable and long-term changes in their children's behavior by achieving maintenance of knowledge and skills, an additional desired outcome of BPT programs is for parents to potentially *generalize* the training concepts to address different behaviors that were not the focus of the original training. Parents of children with ASDs face the need to address a wide range of behavioral and developmental issues over the course of their child's life. Due to the chronic and complex nature of the ASD diagnosis, once parents master the skill of addressing one behavior or developmental concern, another issue is likely to present a challenge to the child and the family. However, if it were possible to demonstrate that by giving parents a broad base of effective skills and strategies to address a specific behavioral issue within a BPT program and for parents to then generalize these skills, the BPT program would then have high clinical utility. If, for instance, following the implementation of a behaviorally-based BPT program to address children's sleep issues, parents were shown to use the same underlying behavioral principles (i.e., antecedent management, extinction, reinforcement, stimulus control procedures) to 1) address their children's other behavioral issues, 2) address a different child's behavioral issues, or 3) train other individuals who care for their children, the BPT program would be seen as a powerful clinical tool producing broad-ranging treatment effects.

A limited number of studies evaluating *generalization* of BPT skills have included follow-up measures that assess the degree to which parents generalized their use of a particular intervention to use it in various settings, train others to implement the intervention, address different behaviors, and use it to address behaviors in their other children (Koegel, Glahn, & Nieminen, 1978; Laski, Charlop, & Shreibman, 1988). At the current time, there are no published studies that have investigated the generalization of parent skills following a BPT program focusing specifically on addressing sleep problems in children with ASD. The few studies that have investigated generalization of parent skills following BPT programs focused on behaviors other than sleep and were also conducted many years ago, but demonstrated that generalization of parent skills does occur.

Laski et al. (1988) provided an example of how generalization of parent skills might be evaluated. In their 1988 study, Laski et al. conducted an evaluation of their BPT program to address speech behaviors in four children with ASD and four children with echolalia using the Natural Language Paradigm (NLP). The investigators monitored parents' use of the intervention across settings and with their other children, which revealed that seven of the eight parent participants had generalized the use of this intervention effectively in both ways. Similarly, Koegel et al. (1978) evaluated generalization of teacher, parent, and child behaviors in a BPT program focusing on teaching children target behaviors relevant to their developmental goals. The results of this study indicated that several variables may be responsible for parents' ability to generalize their skills in teaching their children. Among the variables cited by Koegel et al. (1978) for successful generalization were the use of specific instructions in the particular behavioral concepts taught, visual and auditory models of correct procedures, the demonstration of correct and incorrect examples, and practice over time.

2.2.11 Parent Stress and Children's Sleep Behavior

Parents of children with ASD display high rates of stress associated with caring for their children (Hastings, 2003; Lecavalier, Leone, & Wiltz, 2006). Because children with ASD show increased rates of sleep disturbance (Hering et al., 1999; Patzold, Richdale, & Tonge, 1998; Richdale & Prior, 1995) and this problem is likely to further contribute to parents' stress (Chu & Richdale, 2009), interventions to address sleep problems should aim to show a decrease in parental stress. Wiggs and Stores (2001) conducted a study to evaluate parents' stress in 15 families before and after participation in a treatment to address children's sleep problems and in 15 families who did not receive treatment. For the 15 parents whose children received treatment to address sleep problems, the results showed a marked decrease in stress, an increase in perceived control and satisfaction with children's sleep. Whereas, parents in the control group showed only aspects of increased perception of control, satisfaction with children's sleep, and a persistence of maternal sleepiness. A follow-up study assessing parental stress would most fully assess the wide-ranging effects of a BPT program to address sleep disturbances.

2.2.12 Assessment of Parent Experience and Perception

A combination of qualitative research methods such as semi-structured interviewing as well as quantitative methods have been employed in research with children with autism (Morin & Reid, 1985). Quantitative methods are especially useful in identifying changes that may be objective and measurable (i.e., using dimensions such as frequency, duration, etc. of particular behaviors) between and within groups of children in intervention research. However, investigations seeking to gather richer and more detailed information regarding parents' perceptions of performance and experience in the implementation of behavioral interventions would aid in the analysis of BPT

programs on the whole. An example of how qualitative interviewing aided in identifying themes from personal experiences was shown in Carrington and Graham's (2001) study.

Carrington and Graham (2001) employed a case study of two teenagers with Asperger syndrome and their mothers to develop an understanding of the challenges faced by children in this population at school. Data were collected through the use of semi-structured interviews to identify themes in the perceptions offered by the teenagers and their mothers. Inductive analyses of transcriptions from the semi-structured interviews offered a fuller understanding of experiences. Specifically, four themes were identified through these analyses including: (1) developmental differences; (2) problems associated with the general characteristics of Asperger syndrome; (3) stress; and (4) masquerading. Whereas the first three themes were consistent with the literature on children with Asperger syndrome and their perception of school experience, the final theme of children feeling as though they are 'masquerading' during school was a novel finding that may not have been identified without the use of the qualitative interview. To date, there have not been any published reports including qualitative data reporting parents' experiences and perceptions following participation in a BPT program for children with ASD.

2.3 SUMMARY OF LITERATURE REVIEW AND RATIONALE FOR FURTHER RESEARCH

Sleep problems among children with ASD have been addressed with many of the same behavioral interventions that have shown to be effective among children who are developing typically. These reports have suggested the emerging effectiveness of behavioral procedures. Bedtime routines, faded bedtime procedures, extinction procedures, stimulus fading, and scheduled awakenings have been evaluated to address sleep disturbance in children with ASD and have been examined in two literature reviews (Turner & Johnson, 2012; Vriend, Corkum,

Moon, & Smith, 2011). The majority of studies in these recent literature reviews have involved small sample sizes and primarily utilized single subject designs with limited follow-up information.

Behavioral parent training (BPT) has been shown to be a feasible, sensible, and costeffective approach to treating sleep problems in children with ASD. Since BPT involves didactic sessions between a trained therapist and a parent, *knowledge of behavioral principles* is the key intervention component that parents then apply to address children's behaviors. Further, parents' maintenance of knowledge of behavioral principles may lead to continued application of behavioral principles, and thus maintained behavioral outcomes in children. Only two studies have evaluated knowledge of behavioral principles after staff-members' (St. Lawrence, Hansen, & Steele, 1985) and parent training (Ingersoll & Dvortcsak, 2006). Neither of these studies compared behavioral outcome data to knowledge of behavioral principles, therefore this potential relationship remains unclear. In addition to possessing knowledge of behavioral principles to address specific target behaviors, *generalization of knowledge* is also a desired outcome of any BPT program. There is a dearth of research assessing the maintenance and generalization of knowledge of behavioral principles and its possible relationship with target behavioral outcome data.

Studies evaluating BPT programs to address sleep problems in children with ASD have not included long-term outcome data on child behaviors or parent stress. Although a few studies have evaluated children's sleep behavior one to two years post-training (France & Hudson, 1990; Milan et al., 1981; Weiskop, 2005; Williams, 1958), the majority of studies evaluating sleep interventions have included follow-up measures only up to six months post-training. In addition to the core sleep problems children present, parents of children with ASD who have sleep

problems show high rates of stress. In Wiggs and Stores' (2001) study, once children's sleep problems were addressed, parents' ratings of stress decreased significantly. A study evaluating long-term outcomes of children's sleep behavior and parent stress following training would provide greater evidence for the durability of treatment. Additionally, it is critical for a longterm assessment of a BPT to include a qualitative interview component allowing for parents to report on perspectives and experiences following training. In doing so, this contribution may serve to identify potentially broader clinical effects of the BPT program, such as improvements in other behavioral or developmental areas of the child's life which serve to enhance the clinical utility of the program as a whole.

A follow-up study to a randomized controlled trial (RCT) evaluating a BPT to address sleep problems assists in advancing the literature base on BPT. Specifically, a follow-up investigation identifying whether parents in a BPT group applied knowledge of behavioral principles to a superior degree on a knowledge-based assessment than parents who only receive a comparison training program 6-12 months following training determines the long-term maintenance of this knowledge. Such a comparison provides an indication of whether the knowledge and application of behavioral principles is present in parents simply as a result of being parents or if gaining this knowledge requires additional explicit training. Further, because the goal in parents showing maintenance of knowledge extends to the impact this knowledge has on parents' use of behavioral methods, it is necessary to then examine children's sleep behavior at follow-up as well to determine this effect. Results of this investigation have the potential to contribute to the identification of reliable factors associated with maintenance and generalization of parent knowledge 6-12 months following BPT programs specifically to address sleep problems in children with ASD.

3.0 METHODS

The purpose of this study was to evaluate parents' knowledge and generalization of behavioral principles, children's sleep behavior, parents' ratings of stress, and qualitative statements about perspectives on the program 6-12 months following five sessions of either a multi-component behavioral parent training (BPT) program to address sleep problems or a psycho-educational (PE) program. Specifically, this study was designed to answer the following research questions: a) What are parents' ratings on maintenance variables (i.e., children's sleep behaviors and parents' reported stress) at a 6-12 month follow-up? b) What are participants' scores on the Knowledge Assessment 6-12 months following participation in BPT or PE? c) Are there relationships between maintenance variables (children's sleep and parents' stress at follow-up) and demographic variables (participants' education and income levels) with participants' scores on the Knowledge Assessment at follow-up? d) What do parents report in a qualitative interview inquiring about their experience participating in BPT or PE 6-12 months later?

3.1 TREATMENT OF SLEEP DISTURBANCES IN CHILDREN WITH ASD: A RANDOMIZED CONTROLLED TRIAL

Because this study was a follow-up investigation to an ongoing randomized controlled trial, a brief overview of the initial study is necessary. The current trial intended to measure the efficacy of the BPT program using the PE program as a comparison group for parents of children between the ages of 2 and 6 years with ASD and significant sleep disturbance. Outcome measures for both groups included sleep diaries, parent-completed sleep questionnaires, and actigraphy. The BPT program was focused on dispensing a standardized package of behavioral programs to teach parents to train their children to develop more appropriate sleep behaviors. The current structure of the BPT program was modeled after one developed as a part of the Research Units on Pediatric Psychopharmacology - Psychosocial Interventions – Autism Network (RUPP-PI Autism Network) (Johnson et al., 2007).

Whereas the BPT intervention was the active treatment under evaluation, a comprehensive psycho-educational (PE) program for parents served as the comparison group to control for the effects of time and attention given to families by therapists. All BPT and PE sessions were delivered in an individualized manner with at least one primary caregiver for the child (spouses or other caregivers were invited to attend sessions as well) and a therapist who was cross-trained to deliver both the BPT and PE packages. All sessions were delivered in the Autism Center clinic and were videotaped for reliability purposes. Additionally, therapists assessed the degree to which parents participated, responded correctly and completed activities for each goal outlined in individual sessions for both BPT and PE programs. This therapist assessment of parent involvement during sessions is referred to as *parent adherence*. At the time of this paper's submission, 15 families have completed the BPT program, whereas 18 families have completed the PE program.

3.1.1 Behavioral Parent Training (BPT) Program

The BPT program was packaged to include five core (required) 60-90 minute standardized sessions between the parent and therapist covering the following topics: A) behavioral principles for sleep and bedtime problems; B) prevention techniques and bedtime routines; C) procedures for extinction and reinforcement of behaviors; D) faded bedtime and stimulus control procedures; E) generalization and maintenance of behaviors. These sessions were assembled into a manual with a script for each session for standardization purposes. However, each session presented opportunities for individualization and options to tailor the intervention programs to

each family's needs. In addition to the five core sessions, two sets of optional or "flex" materials were available for parents whose children struggle 1) with compliance to adult directives and/or 2) children who demonstrate nighttime fears. If parents reported that either compliance and/or nighttime fears were a concern, then the therapist attempted to provide the appropriate optional session within the time-frame of a core session in a timely fashion to help the parent address these concerns. Although the sequence for the latter four sessions was relatively flexible, the first session was considered necessary to be delivered first, as it laid the groundwork for teaching parents learning theory and the model that was used to address their child's behaviors throughout the study. Parents were provided video vignettes and activities to verify their understanding of the behavioral concepts, but parent trainers did not provide direct instruction or direct observation of parent implementation in the families' homes at any point.

3.1.1.1 BPT Session A. In the first session, parents were taught that the stimuli and events in their children's environment play a role in their behavior and that modifying the events occurring before and after a behavior have an effect on the occurrence of that behavior. Parents were taught to define behaviors in a manner that is measurable and to identify antecedents and consequences surrounding behaviors from vignettes via activity sheets and video clips of a child and caregiver. Additionally, within this session, parents brought with them recordings of antecedent-behavior-consequence (A-B-C) data they were taught to record during the baseline phase prior to attending the first session, sleep diary recordings for five consecutive days, and corresponding actigraphy data. Evaluating these data with parents during this first session allowed for the therapist to verify that the parent was effective at identifying these events or stimuli surrounding their child's behaviors, and it also served to inform the therapist about the

behavioral contingencies currently in place which may evoke and maintain the behavior(s) disturbing sleep.

3.1.1.2 BPT Session B. The second core session focused on prevention techniques (antecedent management) of the child's behaviors. This topic covered a wide range of strategies, such as the implementation of a bedtime routine that is most conducive to sleep (i.e., resequencing nighttime activities by incorporating more reinforcing and calming activities as the child approaches their bedtime) and selecting an appropriate time for the child to be put to bed. Within this session, parents were taught about a variety of factors that help to promote appropriate sleep behaviors in their child.

3.1.1.3 BPT Session C. The third session in the package included teaching parents to use positive reinforcement and extinction to address children's behavior. Whereas the antecedent management of behaviors session focused on the events preceding problem behaviors surrounding sleep, the reinforcement and extinction session taught parents to evaluate the consequences they might be able to control following their child's problem behaviors. Parents were guided through several activities where they were taught to use graduated extinction and planned ignoring to decrease problem behaviors disturbing sleep. Additionally, within this same session, parents were guided through activities that taught the principle of reinforcement and assisted in identifying reinforcers that may help to increase desired behaviors. Video vignettes, activity sheets, and individualized procedures based upon the child's preferences and parent's input were all used to teach the parents to implement reinforcement and extinction procedures to address the child's sleep disturbance.

3.1.1.4 Session D. A fourth session was conducted which intended to teach parents to implement a faded bedtime routine based upon the child's current sleep schedule, and teach the

child appropriate sleep association (stimulus control) procedures for the child to learn to fall asleep following appropriate cues in the environment. Parents were guided through activity sheets that outlined case study vignettes of children who required a faded bedtime routine due to fragmented sleep or night wakings. Parents were also given a case study vignette involving a child who falls asleep only with specific stimuli (i.e., blanket and lidded cup) that must be replicated in order for sleep to occur. Using these activity sheets, parents were asked to identify solutions to remedy the child's sleep disturbance using the newly introduced faded bedtime routine procedures as well as the stimulus control procedures.

3.1.1.5 Session E. Following these four core sessions (and any optional sessions), parents were given a final session which focused on teaching the parent to address their child's generalization and maintenance of these newly acquired appropriate sleep behaviors. This final session focused on teaching the parent to identify whether their child's sleep behaviors have maintained or continued to improve, whether these changes were observed by all caregivers and locations where the child sleeps, whether there is the possibility that the child could be reinforced in an adventitious manner for their undesired behaviors, and whether the child's reinforcers continue to be varied and appropriate.

Sessions	Topics Addressed	In-session Activities
A. Basic Behavioral Principles	 Introduced overall goals of the program. Introduced concepts of antecedent, behavior, and consequence model. Introduced the concept of the functions of behavior. Introduced how to 	 From a list of 16 words, participants identified words that may be defined behaviorally (i.e., objective, measurable). * Participants role-played with therapist two brief scripts of exchanges between a mother and grandmother describing child's sleep behavior using behavioral and non-behavioral terms. Participants identified antecedent triggering behavior in 3 fictional single-sentence descriptions of child's problem behavior; 2 of

BPT Program Session Outline

B. Prevention Techniques & Bedtime Routines	 evaluate and monitor behavior. Reviewed completion of sleep diary form. Discussed preventive techniques. Developed daily schedule as well as bedtime schedule / routine. Developed visual schedules. Developed social stories when appropriate. 	 these descriptions involve sleep-related problem behavior. Participants identified antecedents, behaviors and consequences for 2 (4-5 sentence-long) descriptions of sleep-related problem behavior. Participants completed a chart outlining child's daily routine beginning when the child wakes and ending when child goes to sleep (e.g., time, activity, comments, indicate if problem or reinforcing activity). Participants watched video vignettes of sleep-related problem behaviors and were asked which of the 6 prevention strategies discussed would have been useful in preventing the behavior. Participants created revised bedtime schedule for child including: time when routine began, steps to complete routine, goal bedtime and other specifications (e.g., use of visual schedule, Social Story, extinction, reinforcement, addressing sleep association, etc.).
C. Reinforcement & Extinction Procedures for Bedtime Struggles, Night Wakings and Early Morning Wakings	 Introduced concept of reinforcers and taught contingent implementation of reinforcement. Introduced concept of extinction / planned ignoring to decrease behaviors. Introduced use of different extinction techniques to specifically address sleep problems (bedtime struggles, night wakings, early morning wakings). Decided upon reinforcement and extinction, and scheduled awakening procedures to implement as appropriate. 	 Participants watched 4 video vignettes of children engaging in problem behavior and parents' consequent responses. Participants were asked which of the extinction or reinforcement strategies would be useful in changing future behavior. * Participants identified at least one example of a primary, social, material, activity/privilege, and token reinforcer for their child. * Participants read 8 steps describing how to use reinforcement to change behavior. * Participants worked with therapist to create a plan to use extinction by responding to 5 questions describing behavior to be decreased, type of ignoring, expectations of child's response, contingency plan for if behavior worsens, and data collection. ± Participants worked with therapist to create a plan to use reinforcement by responding to 6 questions describing the behavior, reinforcement to be used, how to deliver reinforcement immediately and contingently, maintaining reinforcer value and ways in which to pair social and material reinforcement. ±

D. Delayed Sleep Onset & Sleep Association Procedures	 Introduced the concept of stimulus control and its relationship to sleep behaviors. Introduced faded bedtime routines as well as review bedtime routine. Introduced teaching new sleep associations. Developed specific procedures for teaching new sleep associations. 	 Participants read a 5 sentence-long vignette describing a child that experiences delayed sleep onset and were asked to describe a strategy to solve this sleep problem. Participants read an additional 2 sentences following up on the previous vignette describing the outcome of the parents' faded bedtime procedure resulting in the child falling asleep too quickly. Participants were asked to provide advice to modify the faded bedtime procedure to have the child fall asleep within 20 minutes of being in bed. Participants read 2 2-3 sentence-long vignettes describing a child's sleep association problem and were asked to provide suggestions for addressing these sleep association problems. Participants worked with therapist to create a 5-step faded bedtime procedure for their child.
E. Booster & Maintenance Session	 Revised and "tweaked" procedures / techniques based on review of sleep diary data and parent report of progress. Discussed strategies to promote maintenance of behavior change. Generated ideas of what to do if changes do not / have not been maintained. 	 Participants responded to all 6 questions on the maintenance and generalization activity sheet (e.g., Have the child's improvements in bedtime behaviors and sleep stayed the same or continued to improve? Has the child's improvement in bedtime behaviors and sleep been observed by all caregivers? Has the child's improvement in bedtime behaviors and sleep been observed in all places where the child sleeps? Could the child be reinforced for undesired bedtime or sleep behaviors in other situations? Has the child's improvement in bedtime behaviors and sleep been reinforced by all caregivers and sleep been reinforced by all caregivers and sleep been where the child's improvement in bedtime or sleep behaviors in other situations? Has the child's improvement in bedtime behaviors and sleep been reinforced by all caregivers and in other places where the child sleeps? Are a variety of reinforcers being used?)

* Activities that *do not* involve sleep-related problem behaviors.

± Activities that may or may not involve sleep-related problem behaviors.

3.1.2 Psycho-educational (PE) Program

As with the BPT package, the PE package also incorporated 5 separate 60-90 minute sessions

delivered by a therapist to a parent, but did not include any optional sessions. The five sessions

included A) overview of the PE format and of the ASD diagnosis; B) understanding and using clinical assessments and evaluations; C) developmental issues common in children with ASD over time; D) advocacy and support services for children with ASD; E) treatments and treatment planning for children with ASD.

3.1.2.1 PE Session A. The first session in PE (Session A) served to have the parent share the story of their child's diagnosis and to build a therapeutic relationship. Parents were given a handout with an overview of the five sessions of the PE program and the topics that were covered. Throughout the course of the first session, parents were asked to answer several questions in order to discuss their current experience as a parent of a child with an ASD. The therapist asked these questions and then discussed and reflected upon the parents' responses in order to build rapport and better understand the family's current situation. Additionally, parents were shown three brief (3-5 minute) video clips of the assessment of social interaction and communication deficits as well as repetitive behaviors in order to demonstrate ASD characteristics. Parents were then asked to discuss aspects of their child's development or behaviors that indicated the presence of these characteristics.

3.1.2.2 PE Session B. The second session (Session B) assisted parents in learning more about the types of assessments their child had received and the interpretation of results. The therapist asked the parents to bring with them copies of their children's assessment reports from previous evaluations. The therapist then talked with the parent about what the various assessments measured and how to interpret each score. Parents were then asked to complete a worksheet for each assessment that was conducted on their children as an exercise in recalling the type of assessment, outcome, and recommendations for their child from previous evaluations.

Therapists also discussed any remaining issues or questions parents had regarding their child's assessment process and access to services.

3.1.2.3 PE Session C. The third session (Session C) was dedicated to developmental issues and served to prepare parents for the potential changes and transitions the child underwent as they continued to develop with a diagnosis of ASD. In this session, parents discussed common issues in infancy, preschool, middle childhood, adolescence, and adulthood. Parents were encouraged to share concerns as well as ask questions and discuss services and resources available to the child over time. Parents were asked to complete two worksheets during this session. The first worksheet asked parents to list or remark on specific concerns during their child's infancy and preschool years, whereas the second worksheet asked parents to explore concerns they had about their children's future developmental stages (middle childhood, adolescence, and adulthood).

3.1.2.4 PE Session D. The fourth session focused on advocacy and support and provided parents with important resources and knowledge about their role as an advocate for their children as they continue to receive educational and therapy services. In this session, parents were provided with a comprehensive list of resources and organizations focused on advocacy for families with children with ASD. Additionally, parents were given worksheets asking them to list informal sources of support in their lives (e.g., family members, friends, neighbors, other community members) that could be helpful in caring for their children with ASD.

3.1.2.5 PE Session E. The last session was reserved for a discussion of a broad range of potential treatments the child might receive and taught parents to make data-based decisions on their child's progress. Specific treatments discussed included treatments out of the Applied Behavior Analysis (ABA) treatment model (Discrete Trial Therapy, Verbal Behavior),

educational and psychosocial models, related/ancillary therapies (speech language pathology, occupational therapy, and physical therapy), medication therapies, complementary and alternative therapies. This session ended with a discussion of the child's current treatment program and gave parents an opportunity to discuss changes or additions to this program with the therapist. None of the sessions in the PE package referenced the treatment of sleep behavior or sleep disturbance.

Sessions	Topics Addressed	In-session Activities
A. Autism Diagnosis	 Importance of the diagnosis Family's adjustment to the diagnosis Prevalence Etiology Review of service delivery models 	 Participants reviewed topical outline of 5-session PE program. * Participants responded to 6 questions about their child's developmental concerns, professional care provided to child, stressors related to caring for child, family strengths, and family support for child. * Participants watched 3 videos depicting the core concerns of ASD and discuss their responses with therapist. *
B. Understanding & Interpreting Clinical Evaluations	 What do IQ tests measure & what do the scores mean? What are adaptive behavior measures & what do the scores mean? Speech, language and communication measures & their meaning Fine motor measures & their meaning Interpreting behavior rating measures 	 Participants reviewed 4 steps of the assessment process using a diagram provided. * Participants reviewed with therapist previous evaluation reports and assessment protocols previously completed for child. Therapist identified and explained various types of assessments and provided interpretations of scores reported. * Participants summarized up to four assessments conducted on their child, along with an interpretation of the results and recommendations that followed. *
C. Developmental Issues	 Current developmental level and expectations Lifespan issues (Childhood, Adolescence, Adulthood) 	 Participants completed a worksheet describing the developmental concerns their child showed during infancy, early childhood and preschool years. * Participants completed a worksheet

PE Program Session Outline

D. Advocacy and Support Services	 National and local support services Parent to parent contact Advocacy services and how to use them 	 describing their concerns for their child's development and functioning as they enter middle childhood, adolescence and adulthood. * Participants reviewed a list of local and national resources and contact information covering: general advocacy, financial/grant support, legal services and family support. * Participants completed a worksheet outlining informal supports to assist in the care and advocacy of their child, including: family, friends, neighbors and other community members in their lives
E. Treatments & Treatment Planning	 Information on evidence- based / best practices Information on other alternative, supplementary treatments Review of current services for child Discuss progress and current concerns Discuss other treatment options available for child 	 who may provide support. * Participants reviewed current services their child is receiving (e.g., educational, behavioral health, or ancillary service provision). * Participants shared concerns regarding their child's current treatment program. *

* Activities that *do not* involve sleep-related problem behaviors.

± Activities that may or may not involve sleep-related problem behaviors.

3.2 PARTICIPANTS

Participants were at least one parent of 10 children from each group (BPT or PE) who completed

the randomized controlled trial at the Autism Center at Children's Hospital of Pittsburgh 6-12

months prior to their enrollment in this study.

3.2.1 Inclusionary Criteria

Participants needed to have participated in all five sessions of the BPT or PE programs of the

randomized controlled trial (including all assessments at baseline, week 4, and week 8 time

points of the RCT) to be included in this follow-up study. Therefore, parents in the follow-up

study had a child who 1) ranged in age between 2 and 7 years (given the time since participation

in the RCT), 2) had a diagnosis of ASD, and 3) had a history of significant sleep disturbance (i.e., at least one of the following sleep disturbances demonstrated over 4 consecutive weeks: bedtime resistance; delayed sleep onset; sleep association problems; nighttime wakings; and morning wakings).

3.2.2 Exclusionary Criteria

The exclusionary criteria for this follow-up study were the same for the RCT study. Parents with children with a DSM-IV diagnosis of Rett's Disorder or Childhood Disintegrative Disorder were excluded from participation. Also, parents of children with a known serious medical condition or psychiatric diagnosis that would require alternative treatment (e.g., psychotic disorder, major depression) or who were inpatients in a hospital facility did not participate. In order to control for treatment confounds, parents of children who were currently taking prescribed psychotropic medication or medication or supplements to target sleep disturbance (e.g., melatonin) were not permitted to participate. If a child was on medication for sleep which was not effective, a wash out period of 2 weeks was required before inclusion. Parents with children with evidence of sleep apnea, restless legs, or periodic limb movement during sleep, or a circadian-based sleep disorder (e.g. delayed or advanced sleep phase syndrome) based on screening measures and other available information were not permitted to participate in this study. Finally, parents of children showing evidence of having other possible underlying medical etiologies for the sleep disturbances were not permitted to participate.

3.2.3 Similarity of the BPT and PE Groups for Comparison

Because this follow-up study is a comparison of two different groups, it is relevant to discuss the similarity of these two groups for comparison. Measures were taken to ensure that the BPT and PE groups were sufficiently equivalent for comparison within the previous RCT study. First, the

inclusion criteria for participation in the RCT ensured that children were approximately the same age, had an ASD diagnosis, and presented with similar severity and type of sleep disturbances. Therefore, at the start of the RCT (before participants were randomized into one of the two groups), the groups demonstrated a degree of similarity for comparison. Secondly, randomization of participants to either the BPT or PE group ensured that the two groups were comprised of participants that were equally likely to have participated in either group. Therefore, participants' ultimate group assignment was due only to chance and not due to any participant demographic factors. Because the sample for this follow-up study included 10 participants from both the BPT and PE groups, the measures taken to ensure similarity between the groups for the RCT also ensured group similarity for this follow-up study. This comparison provided some indication of whether the knowledge and application of behavioral principles is present in parents simply as a result of being parents or if gaining this knowledge requires additional explicit training.

3.2.4 Recruitment of Participants

Parents that had previously participated in the BPT or PE condition of the RCT study were sent a letter informing them of the study and inviting them to participate in this brief follow-up investigation. Parents were given the researcher's contact information and were asked to contact if they wished to participate. The researcher then scheduled an appointment for the follow-up visit to take place.

3.3 STUDY CONTEXT AND SETTING

The study took place in the homes of child and parent participants. The researcher traveled to individual families' homes at a convenient time for the family to collect the data for each of the assessments. These sessions lasted approximately 90 minutes. All sessions were completed with

the parent who had attended the sessions for the RCT, except in one case wherein the second parent also attended the meeting but did not complete the assessments.

3.4 MATERIALS

At the follow-up visit, the researcher brought paper copies of all questionnaires and a writing utensil for parents to respond. A laptop computer was used to display a PowerPoint presentation. This PowerPoint presentation contained slides that displayed the first 15 questions (one question per slide) on the Knowledge Assessment (KA). A total of 10 brief (10-30 second) video vignettes were also displayed along with several of the questions in order to depict the scenarios being described in the KA. The remaining 30 questions on the KA were asked by the researcher with parent responses recorded by the researcher. Additionally, a digital audio recorder was used to record participants' responses to interview questions for later transcription and analysis.

3.5 VARIABLES

3.5.1 Dependent Variables

The dependent variables for this study consisted of parent responses from four assessments and qualitative interview questions that were collected during one home-visit.

3.5.1.1 Parent knowledge measure. Parents in the follow-up study were asked to complete a knowledge assessment 6-12 months following the end of the BPT or PE program. The Knowledge Assessment, a measure developed by the researcher, was used to assess parents' knowledge of behavioral principles and procedures as well as information provided during the PE program. This was the first occasion any of the participants completed the KA.

Knowledge Assessment. An assessment was administered to parents at this follow-up visit to evaluate knowledge of behavioral principles to address sleep problems (pertaining to the BPT program) and knowledge provided on various topics of the PE program. The Knowledge

Assessment (KA) was developed as a curriculum-based assessment to evaluate parents' knowledge of the concepts taught during BPT and PE. The items on the KA were specifically formulated based upon the goals for parent adherence for sessions A through D of the BPT program and B through E of the PE program. Because Session E of the BPT program covered maintenance and generalization and did not present new information, this section was omitted from the KA. Similarly, because Session A of the PE program was focused on building rapport with the parent and discussing their particular child, this section was omitted from the KA.

Because it was not necessary for parents to be able to recall the names of specific behavioral principles in order to use strategies effectively, an application-based approach to assessing parents' knowledge of BPT material was employed. The KA assessed parents' knowledge in the same manner as was used in a learning activity during the course of the BPT program. Specifically, parents were given video case vignettes, worksheets, and activities and were asked questions relating to the information presented. To assess knowledge pertaining to the BPT curriculum, fictional case vignettes were provided in the KA to evaluate parents' knowledge in identifying appropriate behavioral methods to address common sleep behavior problems in children with ASD. In order to assess knowledge from the PE program, fictional case vignettes were provided in the KA to evaluate parents' knowledge of ASD-related issues. (See Appendix B for Knowledge Assessment)

Validity of Knowledge Assessment as a Measure of BPT and PE Knowledge. Given that the KA was a newly developed measure to assess parent knowledge to address sleep problems in children with ASD, it is necessary to describe how the KA related to the objectives of each session of the BPT and PE. During the course of both the BPT and PE programs, parent therapists completed an assessment of parent adherence to determine the degree to which the

parent was engaged, attentive, and actively learning during the course of each session. The items of the parent adherence rating scale that stated specific goals for parent behavior during the session were selected to be repeated within the KA. For example, within session A of BPT, parents were given an activity sheet with various terms written on it and were asked to identify the terms that were behavioral and those that were non-behavioral. Because that item assessed parents' knowledge of what was taught within the session, the same item was used in the KA to determine if parents possessed this knowledge 6-12 months following participation in the BPT or PE programs. The KA was comprised of 20 items covering BPT knowledge, 20 items covering PE knowledge and five items that assess generalization of BPT principles. The KA was scored by assigning one point for each of the 45 questions.

Objectives of Parent Adherence Pertaining to Knowledge	Knowledge Assessment	
BPT Session A:		
Parents discriminated between behavioral and non-behavioral terms as determined from completion of activity sheet.	Item 1: Presented behavioral and non- behavioral terms with the same instructions as in the BPT manual.	
Parents demonstrated ability to identify antecedents, behavior and consequences on activity sheet.	Item 2-3: Used a similar activity sheet and the same instructions as in BPT manual.	
Parents demonstrated ability to identify antecedents and consequences to bedtime / sleep behaviors from videotape vignettes.	Item 4-5: Used similar video vignette and asks the same questions as in BPT manual.	
BPT Session B:		
Parents provided a prevention strategy for each scenario in 3 video vignettes.	Items 6-10: Showed 5 similar video vignettes and asked the same questions as in BPT manual.	
BPT Session C:		

Parents correctly identified which reinforcement step(s) had been broken and made appropriate suggestions for correcting problem within 2 video vignettes.	Items 11-12: Used similar video vignettes and ask the same question as in BPT manual.	
Parents correctly identified which extinction rule(s) had been broken and made appropriate suggestions for correcting problem within a video vignette.	Item 13-15: Used a similar video vignette and ask the same question as in BPT manual.	
BPT Session D:		
Parents identified the errors made in the implementation of faded bedtime procedures on the activity sheet.	Item 16-18: Used similar activity sheet and the same instructions as in BPT manual.	
Parents identified solutions to sleep association problems on 2 fictional case vignettes on the activity sheet.	Items 19-20: Used similar fictional case vignettes and the same instructions as in BPT manual.	

Validity Table for PE Sessions

Objectives of Parent Adherence Pertaining to Knowledge	Knowledge Assessment	
PE Session B:		
Parents identified their child's strengths and weaknesses based on the available assessment (or identify strengths and weaknesses from the example case).	Items 21-25: Presented information about a fictional child and parents were asked to identify strengths and weaknesses in the child's development.	
PE Session C:		
Parents identified their concerns and expectations regarding their child's development over time.	Items 26-30: Presented fictional case vignettes of children showing concerns specific to developmental stages discussed in PE manual.	
PE Session D:		
Parents had an opportunity to gain more information about local and national advocacy services.	Items 31-32: Used fictional vignettes of families with advocacy needs similar to what is described in the PE manual and asks	

	parents to identify advocacy options.	
Parents gained information about how to	Items 35: Used fictional case vignette of a	
evaluate methods used to address their	family requiring advocacy to address their	
child's treatment or educational goals.	child's treatment and educational goals.	
PE Session E:		
Parents demonstrated an understanding of	Items 36-40: Used the same 5 true/false	
treatments for children with ASD.	quiz questions shown in the powerpoint	
	presentation describing treatments for	
	children with ASD.	

3.5.1.2 Child sleep measure. Parents in the follow-up study were asked to complete a questionnaire reporting their children's sleep behavior 6-12 months following the end of the BPT or PE program. The Modified Simonds & Parraga Sleep Questionnaire (MSPSQ) (Simonds & Parraga, 1982) was given to parents to report on their children's behavior. This was the fourth time participants were asked to complete the MSPSQ, as they had already completed this measure at three previous time-points (baseline, week 4, and week 8 of the RCT).

The Modified Simonds & Parraga Sleep Questionnaire (MSPSQ; Simonds &

Parraga, 1982) was used in this study to measure children's sleep behavior at follow-up. This questionnaire consists of two parts: Part 1 includes items related to the quantity and quality of sleep, whereas Part 2 asks more detailed questions specific to sleep disorders. The MSPSQ was used by Wiggs and Stores in several studies (Wiggs & Stores, 1996; Wiggs & Stores, 1998; Wiggs & Stores, 2004) (see Appendix B). Wiggs and Stores (1996) reported the test-retest reliabilities for a 2 week period to be .83 to 1.0. The questionnaire is comprised of 51 items. A total score was obtained from the 36 items that were amenable to Likert scale scoring that covered common sleep problem categories to include: bedtime resistance / struggles, sleep

onset delay, parasomnias, sleep disordered breathing, sleep anxiety, and daytime sleepiness. Rather than assigning scores ranging from 0-2 for each items as Wiggs et al. (1998) had done for six items, the range was modified to include greater variability. The convention for scoring the 36 frequency items was: never = 0; about once a month = 1; a few times a month = 2; once or twice a week = 3; and many times a week or daily = 4. This scoring convention results in total scores ranging from a minimum score of 0 to a maximum score of 144. The questionnaire has been reported to be acceptable to parents. This measure requires 15 minutes to complete. (See Appendix C for MSPSQ)

3.5.1.3 Parent measures. Parents participating in the follow-up study were asked to complete an additional assessment to evaluate parent ratings of stress. Data on the Parenting Stress Index (PSI; Abidin, 1995) for all participants were collected at all three time-points of the RCT (baseline, week 4, and week 8) and were collected again at this time-point.

The Parenting Stress Index (PSI; Abidin, 1995) aims to assess levels of parental stress. The PSI contains a short form consisting of 36-items intended to be completed by parents of children less than 12 years of age. This measure is comprised of three scales: Parental Distress, Difficult Child Characteristics, and Dysfunctional Parent-Child Interaction. The short form is a 36-item parent-completed questionnaire for families of children 12 years of age and younger. This measure has been used to assess parent stress and parent-child relationships in children with autism and intellectual disabilities (Hassal, Rose, & McDonald, 2005; Montes & Halterman, 2006; Wolery & Garfinkle, 2002). It has been empirically validated to predict observed parenting behavior and children's current and future behavioral and emotional adjustment. The PSI is written at a 5th grade reading level and is comprised of three scales: 1)
Parental Distress; 2) Difficult Child Characteristics; and 3) Dysfunctional Parent-Child Interaction. The three subscales consist of 12 items each and parents rate their agreement with each statement on a 5-point scale. Therefore, a combined maximum total score of 180 points would indicate maximum stress across all three subscales. This measure may be completed in 15-20 minutes. Percentile scores of the PSI will be used in data analysis.

Parent Interview. Following the administration of all assessments, parents were interviewed using a semi-structured series of questions pertaining to their perceptions and experiences 6-12 months following their participation in the study. The questions on this interview form were developed by the researcher in order to gain additional information about parents' experiences and perceptions about their participation in the study at follow-up. This was the first occasion any of these participants were given these qualitative interview questions. (See Appendix E for Interview Form)

3.5.1.4 Interim Services and Events Assessment. Because it is likely that parent participants continue to seek services to address children's developmental and behavioral concerns in the 6-12 month time period following the termination of the RCT study, it was important to obtain information about these services. Therefore, parents were asked to complete a form at the follow-up visit that indicated services the child and/or parent received during this period. The form provided nine possible treatments parents and / or children may have received within the 6-12 month follow-up period as well as a space for parents to report treatments not listed. Parents were asked to report service providers, beginning and end dates, hours per week or dosage (if applicable), whether the treatment was provided on a group or individual basis, and the setting in which the service was provided. Finally, a question asking parents to report on life-changing events during the 6-12 month follow-up period was provided to ascertain

additional information about parent and child experiences post-intervention. This was also the first occasion parents were asked to complete this particular form. (See Appendix E for Interim Services and Events Assessment)

3.5.2 Post-Training Sleep Behavior and Parent Stress Assessment

Prior to conducting follow-up analyses 6-12 months after participants' completion of the training program, it was necessary to demonstrate that BPT participants showed behavioral changes *immediately* following training that were superior to the comparison PE participants. Data that were collected at the 8-week time-point for the BPT and PE groups (the MSPSQ and PSI) were compared to determine whether the BPT group was responsible for change. Without this comparison analysis, it would be difficult to demonstrate maintenance of knowledge 6-12 months following training was responsible for maintained behavioral change.

3.5.3 Independent Variables

The independent variables for this follow-up investigation were the five sessions of BPT or PE that had been provided to parent participants during their previous participation in the RCT.

3.6 PROCEDURES

All procedures were approved by the University Institutional Review Board prior to initiation of the study.

3.6.1 Follow-up Visit

This follow-up visit began with a brief opportunity for the researcher to re-acquaint herself with the family, then complete the informed consent forms and provide associated information. If parents had questions while completing the informed consent form or any of the procedures that would follow, the researcher provided answered them. Then, the researcher provided the parent with a series of assessment forms and questionnaires.

The KA was the first assessment presented and required 45-50 minutes to complete. During the completion of the KA, the researcher presented PowerPoint slides and video vignettes to parents. The researcher read each question on the slides to the parents, played the corresponding video vignette, and recorded parent responses to the multiple choice questions on the KA. Once the slideshow was complete, the researcher continued to present the remaining 30 KA questions to the parents and recorded their responses.

Next, parents rated their children's current sleep behavior using the Modified Simonds and Parraga Sleep Questionnaire (MSPSQ). The researcher provided the paper copy of the MSPSQ and parents completed this questionnaire independently, asking the researcher questions if necessary. The Parenting Stress Index (PSI) was the third assessment administered at this follow-up visit; and the carbon paper form was also given to parents for them to respond independently, asking questions as needed.

Next, the researcher conducted the brief (5-15 minute) qualitative interview with the parent. The researcher confirmed with parents again (since the informed consent process had been completed) that the interview would be audio recorded. Once parents confirmed they were aware of and permitted audio recording of their responses, the researcher started the audio recorder. The researcher then asked each of the five questions, allowing participants to respond fully to each question. Finally, parents were given the Interim Services and Events Assessment and were asked to independently complete the form, asking the researcher to clarify service categories as needed. Later, during data analysis, responses provided on a demographic questionnaire at the baseline time-point of the RCT were used to determine possible relationships between parents' education and income with knowledge.

3.6.2 Data Plan

Data analysis was carried out in several steps. First, descriptive analyses consisted of examination of the distributions of the demographic information of participants to determine similarity between the two groups as well as dependent variables. The resulting descriptive statistics summarized data from individual participants as well as the entire sample. Second, within-subjects analyses were completed within the BPT group to assess the characteristics of responders and non-responders to the treatment. Responders were characterized by a significant reduction in parent reports of sleep disturbances (MSPSQ total composite scores) whereas nonresponders were characterized as those participants that did not show a significant reduction in MSPSQ total composite scores. Additionally, data on supplemental services and events children and parents had received or experienced since intervention (Appendix F) were analyzed for use in this within-subjects analysis to further explore treatments that may have impacted treatment response for particular participants. Finally, it was necessary to examine the assumptions for subsequent statistical techniques. Given that the sample sizes for both the BPT and PE groups were small (n = 10) and that neither the KA nor MSPSQ have normative data to suggest population parameters, all other analyses required non-parametric methods.

4.0 RESULTS

This chapter describes the results of the various assessments at the follow-up visits conducted 6-12 months following parents' participation in either the BPT or PE program. Section One presents the demographic statistics of the 10 participants who completed the BPT program and 10 participants who completed the PE program. Section Two reports the maintenance of parent report of children's sleep behavior and parents' ratings of stress at follow-up. Section Three shows the results of the Knowledge Assessment (KA) that was administered to parents. Section Four reports on the analyses of the relationships between KA scores and children's sleep behavior, parent report of stress and children's sleep behavior, KA scores and parent report of stress, education level, and income. Finally, Section Five provides the results of a qualitative analysis of transcribed interviews with parents on perspectives and experiences following participation in the BPT or PE groups.

4.1 DEMOGRAPHIC STATISTICS OF SAMPLE

In this study, 10 participants who completed a BPT program to address sleep problems in their children with ASD and 10 participants who completed a PE program to learn general information about ASD participated in this follow-up study. The descriptive statistics of demographic data as well as time at follow-up (6-12 months) are provided in Table 1 below for both the BPT and PE groups. Children's and parents' mean ages were nearly equivalent across the BPT and PE groups. The BPT group was comprised of 10 mothers and their children (three females and seven males), whereas the PE group consisted of nine mothers, one father and their children (two

females and eight males). The average number of months post-RCT to the date of follow-up was also nearly equivalent across the BPT and PE groups.

Table 1

Participant Age, Gender, and Follow-up Time Since RCT

	BPT Group $(n = 10)$	PE Group $(n = 10)$
	M (SD, Range)	M (SD, Range)
Mean Child Age (months)	57 (13, 30-74)	58 (13, 34-77)
Gender	80% male	70% male
Mean Parent Age	36 years, 9 months (6 years, 9 months, 24 – 46 years)	33 years, 8 months (4 years, 9 months, 26-40 years)
Mean # Months Post-RCT	7.3 months (2 months, 6-11 months)	7.4 months (2 months, 6-12 months)

Each participant was asked to report on family income (by selecting from five ranges of income values) and parent education level on a demographic form at the time of entry into the RCT (see Appendix D). All ten participants reported family income in the PE group, with a mean of \$50,000-75,000, whereas only nine participants in the BPT group reported a family income, reporting a mean of \$30,000-50,000. All mothers in both groups reported their education level, which was equivalent with an average educational level of "vocational technical training" or "some college." Despite both groups sharing the same average educational level, the group of mothers in the PE group spanned a wider range than the BPT group. Only eight fathers reported their educational level in the PE group whereas nine reported this same information in the BPT group. Overall, fathers in the PE group were more educated than those in the BPT

group, but spanned the same range of educational level across groups. These results are displayed in Table 2.

Table 2

Participant Family Income and Parent Education

		BPT Group	PE Group				
	n	M (SD, Range)	n	M (SD, Range)			
Mean Family Income	9	\$30,000-50,000 (\$15,000; \$15,000->75,000)	10	\$50,000-75,000 (\$20,000, \$15,000- >75,000)			
Mother Education	10	Vocational tech/College (high school – college)	10	Vocational tech/College (high school – graduate/professional)			
Father Education	9	High school – vocational tech (high school – graduate/professional)	8	Vocational tech/College (high school – graduate/professional)			

Parents in both groups also reported on the interim services received across a wide range of categories. Children's psychological services were reported to be delivered entirely by behavioral health and rehabilitative services (BHRS) providers. There were 10 respondents in the PE group that indicated the use of children's psychological services at an average of 13.20 hours per week. The BPT group had eight children report the use of psychological services at a mean of 9.43 hours per week. All of these services were delivered in the home environment. All participants maintained the same BHRS provider agency and number of hours since their participation in the RCT except in the case of one child in the PE group and two children in the BPT group. In each of these cases, the children's service provider staff changed (different behavior specialist consultant or therapeutic staff support), but the number of hours and therapeutic orientation remained consistent.

Children in both the BPT and PE group continued to engage in a variety of therapies and services in the time since their participation in the RCT. In the time since the RCT, the BPT group's data showed two children changed BHRS agencies and therapists. Additionally, two children changed speech language pathology services, one to increase to one full hour of services per week from only 30 minutes per week, and the second child experienced a change in therapists. Also, two children experienced changes in their occupational therapy services, both including a decrease in services from one hour to 30 minutes, and one who also experienced a change in setting from receiving services at home to school. Finally, the BPT group reported two children who recently began engaging in recreational sports as therapy several months after participation in the RCT.

The PE group's data showed one child changed BHRS therapists, one child began receiving physical therapy, one child changed speech language pathology services due to a family relocating to another area and requiring a different therapist to deliver these services, and one of the children began recreational sports as therapy after participating in the RCT. These results are displayed in Table 3.

Table 3

		BPT Group)
п	Hours/Week M(Range)	Setting	n	Hours/Week M (Range)	Setting
8**	9.43 (0-20)	Home	10*	13.2 (4-28)	Home
1	1	Home	0	N/A	N/A
2	0.5 (0-1)	School	1*	0.5 (0-0.5)	Agency
10**	Group (2); individual (8) 1.15 (0.5-2)	Home (2); school (6); agency (2)	8*	Group (2); individual (6) 1.07 (0.75- 2.0)	Home (1); school (4); agency (3)
9**	Group (2); individual (7) .92 (0-1.5)	home (2); school (5); agency (2)	7	Group (2); individual (5) 0.65 (0-1)	Home (2); school (2); agency (3)
2**	Gymnastics (1); horse- riding (1) 1 (0-1)	Setting: agency	4*	Aquatic (1); gymnastics (1); horse- riding (1); yoga (1) 0.87 (0-1)	Agency
	1 2 10** 9**	8** 9.43 (0-20) 1 1 2 0.5 (0-1) 10** Group (2); individual (8) 1.15 (0.5-2) 9** Group (2); individual (7) .92 (0-1.5) 2** Gymnastics (1); horse- riding (1)	8** 9.43 (0-20) Home 1 1 Home 2 0.5 (0-1) School 10** Group (2); individual (8) Home (2); school (6); agency (2) 9** Group (2); individual (7) home (2); school (5); agency (2) 9** Group (2); individual (7) home (2); school (5); agency (2) 9** Gymnastics (1); horse- riding (1) Setting: agency	8** 9.43 (0-20) Home 10* 1 1 Home 0 2 0.5 (0-1) School 1* 10** Group (2); individual (8) Home (2); school (6); agency (2) 8* 9** Group (2); individual (7) home (2); school (5); agency (2) 7 9** Group (2); individual (7) home (2); school (5); agency (2) 7 2** Gymnastics (1); horse- riding (1) Setting: agency 4*	8** 9.43 (0-20) Home 10* 13.2 (4-28) 1 1 Home 0 N/A 2 0.5 (0-1) School 1* 0.5 (0-0.5) 10** Group (2); individual (8) Home (2); school (6); agency (2) 8* Group (2); individual (6) 9** Group (2); individual (7) home (2); school (5); agency (2) 7 Group (2); individual (5) 9** Group (2); individual (7) home (2); school (5); agency (2) 7 Group (2); individual (5) 9** Gymnastics (1); horse- riding (1) Setting: agency 4* Aquatic (1); gymnastics (1); horse- riding (1); yoga (1)

Interim Psychological and Related Services Received

*1 Participant changed services within interim period

**2 Participants changed services within interim period

Reports of the use of medication were also provided in both groups, with one child in the

PE group reporting the use of melatonin to address sleep disturbances in the time since

participating in the RCT. The BPT group contained two children beginning to take melatonin in the time since the RCT, whereas one child began using melatonin in the PE group. These results are displayed in Table 4.

Table 4

Interim Complementary / Alternative Services Received

		BPT Group			PE Group			
	п	Medication / Supplement	Dose	п	Medication / Supplement	Dose		
Medication	2**	Melatonin	1 ml, daily	1*	Melatonin	3 ml, prn		
	1	Tenex	1 mg, daily					
Vitamin	0	N/A	N/A	1	Omega 3	0.5 mg, daily		
Diet	1	GFCF	N/A	3	GFCF (2); GFCF + soy-free (1)	N/A		

*1 Participant changed services within interim period

**2 Participants changed services within interim period

When participants were asked to report on additional events (adverse or otherwise) that may have impacted their experience since their participation in the RCT, two parents in the PE group reported events. First, PE13 reported the death of the child's maternal grandfather and one parent reported having recently (within 2 weeks of follow-up) graduated from a stressful medical residency program (PE33). There were two parents in the BPT group who reported events. First, one parent in the BPT group (PT35) reported that she had separated from her husband but that the child's routine had not changed as a result of this change due to the child's home environment remaining the same and that the father has maintained regular contact with the child. Another parent in the BPT group (PT14) simply reported that her child had begun full-day kindergarten and was no longer taking a nap during the day.

4.2 ANALYSES OF MAINTENANCE OF CHILDREN'S SLEEP AND PARENT STRESS FOLLOWING TREATMENT

Mean and standard deviation statistics as well as mean difference scores (follow-up scores subtracted from week 8 scores) on the MSPSQ and PSI percentile scores were calculated for both week 8 of the RCT (termination of participation in the RCT) and follow-up time points. Higher MSPSQ scores and PSI percentile scores are indicative of a greater frequency of sleep disturbances and responses on items indicating parental stress, respectively. The mean MSPSQ scores for week 8 in the PE group were higher than the mean week 8 scores for the BPT group, indicating the PE group showed greater sleep disturbances following training than the BPT group. The PE group showed a slight reduction in mean MSPSQ scores at the time of follow-up, whereas the BPT group's mean MSPSQ score remained relatively consistent with the week 8 reports.

A similar pattern was observed in both groups in terms of the PSI data. The mean week 8 PSI percentile score for the PE group was higher than the week 8 percentile scores for the BPT group, suggesting the PE group was reporting greater parental stress than the BPT group at the termination of training. However, a reduction in PSI percentile scores was shown to occur in the PE group by the follow-up time-point, yet the BPT group's mean scores remained relatively consistent with a minor decrease from the ratings at week 8. These data are displayed in Table 5.

Table 5

	BPT Group $(n = 10)$			PE Group $(n = 10)$			
	Week 8	Follow-up	Mean Diff	Week 8	Follow-up	Mean Diff	
	M (SD)	M (SD)		M (SD)	M(SD)		
MSPSQ	36.90 (14.14)	36.40 (17.56)	.50	44.50 (18.48)	42.20 (18.84)	2.30	
PSI	66.00 (33.64)	63.75 (30.64)	2.25	70.10 (37.94)	57.80 (37.33)	12.30	

Descriptive Statistics for MSPSQ and PSI Scores

Is there a within-group difference in parent report of children's sleep disturbances at the termination of the study (Week 8) and 6-12 months after the intervention for each group (BPT and PE)? Paired t-tests were conducted within each group to determine if there were significant differences between week 8 MSPSQ and follow-up MSPSQ scores. Although both groups showed a decreased rating of sleep problems at follow-up, the means were not statistically significantly different. The effects for time point on MSPSQ score within the BPT group t(18) = .07, p = n.s. or the PE group t(18) = .28, p = n.s. were not statistically significant. These results suggest that the ratings of children's sleep behavior for both groups remained relatively consistent from the time when participants ended training through the follow-up time point.

Does a group (BPT or PE) show a greater difference in parent report of children's sleep disturbances at the termination of the study (Week 8) and 6-12 months after intervention? The PE group's mean MSPSQ scores for week 8 of the RCT and follow-up indicated a small mean decrease in MSPSQ ratings of sleep disturbance. Alternatively, week 8 MSPSQ data for the BPT group were relatively similar to follow-up reports of sleep disturbances. A Mann-Whitney *U* test was conducted to determine if there was a statistically significant difference in MSPSQ scores across groups. The mean ranks for both groups showed that at both time points (week 8 of the RCT and at follow-up), the PE group had greater MSPSQ ratings than the BPT group. At week 8, the PE group had a mean rank of 11.90, while the BPT group had a mean rank of 9.10. At follow-up, the mean rank for the PE group was 11.50, whereas the BPT group had a mean rank of 9.50. However, there was determined to be no significant difference between the BPT and PE groups' MSPSQ scores at week 8 of the RCT, U = 36.00, p = n.s., or at follow-up, U = 40.00, p = n.s.

Is there a within-groups difference in parents' ratings of stress at the termination of the study and 6-12 months after the intervention for each group (BPT and PE)? Paired t-tests were conducted within each group to determine if there were significant differences between week 8 PSI and follow-up PSI scores. Despite parents' reporting a decrease in stress at follow-up in both groups, these differences were not significant. There was not a significant effect for time point on PSI score within the BPT group t(18) = .16, p = n.s. or the PE group t(18) = .73, p = n.s. Results of this analysis suggest that the ratings of parent stress for both groups did not significantly differ from the time when participants ended training through the follow-up time point.

Does a group (BPT or PE) show a greater difference in parents' ratings of stress at the termination of the study and 6-12 months after intervention? The PE group's mean PSI percentile scores for week 8 of the RCT and follow-up indicate a moderate mean decrease in PSI percentile scores, suggesting PE participants experienced a decrease in stress. Similar to the BPT data for the MSPSQ ratings, the BPT group's mean PSI percentile scores also showed a slight decrease in parent ratings of stress, since termination of the RCT. A Mann-Whitney U test

was conducted to determine if there was a statistically significant difference in PSI scores across groups. There was determined to be no significant difference between the BPT and PE groups' PSI scores at week 8 of the RCT, U = 41.50, p = n.s., and follow-up, U = 49.00, p = n.s. The average rank for the week 8 PSI score for the PE group was 11.35, which was higher than that of the mean rank of the BPT group's week 8 PSI score, 9.65. The follow-up mean rank PSI score for the BPT group was higher than the PE group's mean rank, with 10.60 and 10.40 respectively.

4.3 ASSESSMENT OF PARENT KNOWLEDGE OF BEHAVIORAL PRINCIPLES

Is there a difference between responses to the maintenance and generalization questions on the Knowledge Assessment (KA) for each group (BPT or PE)? All ten participants in both groups completed all 45 items of the Knowledge Assessment (KA). The total correct responses to the Sleep Knowledge, General Knowledge, and Generalization items were then separately summated to create three different sub-scores. The means for these scores are provided in Table 6. Overall, these results show that the PE group scored higher on the General Knowledge questions than the BPT group. Similarly, the mean BPT group's responses on Sleep Knowledge questions were higher than the PE group's responses on Sleep Knowledge items. Finally, the BPT group responded correctly more often than the PE group on Generalization questions.

Table 6

Knowledge Assessment Mean Scores

	BPT Group $(n = 10)$	PE Group (<i>n</i> = 10)	
	M (SD)	M (SD)	Mean Difference Between Groups
Sleep Knowledge Score (20 items)	17.21 (1.73)	13.78 (3.93)	3.43
General Knowledge Score (20 items)	16.17 (2.81)	17.20 (1.47)	1.03
Generalization Score (5 items)	4.40 (1.07)	3.75 (1.44)	.65

A Mann-Whitney *U* test was conducted to determine if there was a statistically significant difference between each of the three KA scores across groups to evaluate the hypothesis that the BPT group would score higher on the Sleep Knowledge and Generalization items than the PE group. The BPT group had a mean rank of 13.40 on Sleep Knowledge questions, whereas the PE group had a mean rank of 7.60. On the General Knowledge questions, the PE group had an average rank of 11.55, while the BPT group had an average rank of 9.45. For the five Generalization questions, the BPT group had an average rank of 12.5 and the PE group had an average rank of 8.50. Despite the differences in mean ranks on each of the KA scores across groups, only one of the comparisons of the three scores across the two groups showed a difference in the expected direction that was statistically significant, the total score on Sleep Knowledge items, U = 21.00, p < .05. The differences between groups' mean scores on General Knowledge items were not statistically significant (U = 39.50, p = n.s.) nor were the total scores on Generalization items (U = 30.00, p = n.s.).

Although the BPT group scored significantly higher on the Sleep Knowledge questions than the PE group, with a mean percentage of 86% of the items correct, the PE group still performed well on these items, scoring 69% correct. In light of the similarly high scores on Sleep Knowledge items from both groups, it was useful to further examine which of the BPT and PE sessions covered in the KA items were answered correctly by each group. Table 7 provides the mean percentage of items correct for each section of the KA by group.

Table 7

		BPT Group $(n = 10)$	PE Group (<i>n</i> = 10)	
		M (SD)	M (SD)	Mean Difference Between Groups
Sleep Knowledge				
	BPT Session A	92% (17%)	80% (21%)	12%
	BPT Session B	88% (16%)	64% (22%)	24%
	BPT Session C	82% (19%)	68% (19%)	14%
	BPT Session D	82% (25%)	64% (27%)	18%
General Knowledge				
	PE Session B	72% (16%)	68% (16%)	4%
	PE Session C	88% (13%)	90% (14%)	2%
	PE Session D	83% (8%)	94% (5%)	11%
	PE Session E	80% (14%)	92% (11%)	12%
Generalization Items		88% (8%)	75% (14%)	13%

Mean Percentage of Correct Items by Session on the Knowledge Assessment

The BPT and PE groups' mean scores for each set of items on the KA suggested that overall, the groups showed a greater difference in the accuracy of responses to the Sleep Knowledge questions than the General Knowledge questions. These results indicated that parents in both groups performed almost equally well on an assessment of General Knowledge regardless of whether they received explicit training. Despite the two groups' greater difference in performance on the Sleep Knowledge items, the PE group still performed relatively similarly to the BPT group.

4.4 RELATIONSHIPS BETWEEN MAINTENANCE, KNOWLEDGE, AND DEMOGRAPHIC VARIABLES

Is there a relationship between parents' responses to the KA and children's current sleep behavior? Within the PE group, Spearman's rank correlation tests (rho) were conducted (n = 10) on parents' responses to the questions on the KA and follow-up MSPSQ scores. None of these tests indicated a statistically significant relationship between the KA scores and the follow-up MSPSQ score within the PE group. The BPT group's (n = 10) Spearman's rank analysis of the possible relationships between KA scores and follow-up MSPSQ scores showed responses on the General Knowledge questions of the KA and follow-up MSPSQ scores were slightly correlated (rs[10] = .02, p = .06) and this approached statistical significance. Responses on the Sleep Knowledge and Generalization items on the KA and the follow-up MSPSQ were not statistically significant.

The data for both the BPT and PE groups (n = 20) were then combined in order to assess relationships between KA scores and follow-up MSPSQ scores regardless of group membership. No statistically significant correlations were found between the responses to General Knowledge questions, responses to the Sleep Knowledge questions, or Generalization questions, and the

follow-up MSPSQ. A summary of all correlation test results between responses on the KA and follow-up MSPSQ scores is reported in Table 8.

Table 8

Correlations between MSPSQ Scores and Responses to the KA

	BPT Group $(n = 10)$	PE Group (<i>n</i> = 10)	BPT + PE (<i>n</i> = 20)
	rs	rs	r
Mean Score on General Knowledge Items	.02	.16	.11
Mean Score on Sleep Knowledge Items	31	41	34
Mean Score on Generalization Items	.50	.06	.0
*n < 05			

*p < .05

Is there a relationship between parents' reports of stress and children's sleep behavior 6-12 months after intervention? A Spearman's Rank correlation (rho) was calculated on the PE group data to determine whether a relationship between PSI and MSPSQ scores existed at follow-up time points. The results indicated that a strong, positive, and statistically significant correlation (rs[10] = .81, p < .01) existed between the parents' ratings of stress and children's sleep behavior from respondents in the PE group. The correlation suggests that parents' levels of stress were related to reports of children's sleep problems. The same correlation test was conducted for the BPT group and revealed a weak, negative, and statistically insignificant correlation (rs[10] = ..14, p = n.s.). These data were then combined to evaluate whether a relationship existed between the PSI and MSPSQ at follow-up regardless of group membership and revealed a moderate, positive correlation that was approaching statistical significance (r =.42, n = 20, p = .06).

Is there a relationship between parents' ratings of stress and parents' responses to questions on the KA 6-12 months after intervention? The PE group data (n = 10) were analyzed using Spearman's rank correlation test (rho) on parents' responses to questions on the KA and the follow-up PSI percentile scores. None of these tests on PE group data indicated a statistically significant relationship between parent stress and responses on the KA. Data from the BPT group were analyzed with Spearman's rank correlation tests of possible relationships between KA scores and follow-up PSI percentile scores were conducted. Responses on the Sleep Knowledge items on the KA and the follow-up PSI showed a moderate, positive, and statistically significant correlation (rs[10] = .7, p < .05), whereas the General Knowledge and the Generalization items were not significantly correlated with PSI scores at follow-up. This correlation indicates that within the BPT group, parents with greater stress at follow-up were more likely to respond correctly to the Sleep Knowledge items. Finally, the data for both the BPT and PE groups (n = 20) were aggregated in order to examine whether relationships existed between variables regardless of group membership. No statistically significant correlations were found for the responses to General Knowledge questions, responses to the Sleep Knowledge questions, or Generalization questions with the follow-up PSI percentile scores when the two groups' data were combined. The results of these correlation tests are summarized in Table 9.

Table 9

	BPT Group $(n = 10)$	PE Group (<i>n</i> = 10)	BPT + PE (<i>n</i> = 20)
	rs	rs	r
Mean Score on General Knowledge Items	.42	.5	.27
Mean Score on Sleep Knowledge Items	.7*	41	08
Mean Score on Generalization Items	.39	29	06

Correlations between PSI Scores and Responses to the KA

**p* < .05

Is there a relationship between parents' responses to questions on the KA and parents' completed education level? Data from the PE group were analyzed using Spearman's rank correlation tests (rho) to determine possible relationships between parents' responses to the questions on the KA and parent education level. It is important to note that, from the PE group, only eight fathers supplied a response for completed education level, whereas all ten mothers reported completed education level. None of the correlation tests between mothers' or fathers' education levels and responses on the KA were statistically significant for the PE group.

A Spearman's rank analysis for the BPT group data was conducted to determine possible relationships between KA scores and parents' completed education level. All ten mothers reported completed education levels whereas only nine fathers provided this information in the BPT group. As with the PE group, the education levels of parents in the BPT group were not statistically significantly correlated with responses on the KA.

The data for both the BPT and PE groups (n = 17) were then combined to assess potential relationships between responses on the KA and parents' education level regardless of group assignment. No statistically significant correlations were found between mothers' completed

education level and the responses to General Knowledge questions, responses to the Sleep Knowledge questions, or Generalization questions. Similarly, no statistically significant correlations were shown to exist between father's completed education level and responses to the Sleep Knowledge questions, or Generalization questions. However, in this combined group sample, responses to the General Knowledge questions and father's education level (r = .47, n = 17, p = .05), yielded a moderate correlation that approached significance. Table 10 contains a summary of these correlations.

Table 10

		BPT	Group	PE Group		BPT	+ PE
		n	rs	п	rs	n	r
Mothers							
	Mean Score on General Knowledge Items	10	04	10	.45	20	.21
	Mean Score on Sleep Knowledge Items	10	09	10	.18	20	.08
	Mean Score on Generalization Items	10	51	10	.41	20	.05
Fathers							
	Mean Score on General Knowledge Items	9	.39	8	.48	17	.47
	Mean Score on Sleep Knowledge Items	9	08	8	.00	17	15
	Mean Score on Generalization Items	9	01	8	18	17	.01

Correlations between Parent Education Level and Responses to the KA

**p* < .05

Is there a relationship between parents' responses to questions on the KA and parents' income? Spearman's rank correlation tests were conducted with PE group data (n = 10) on parents' responses to the questions on the KA and reported family income. None of these tests indicated a statistically significant relationship between KA scores and family income within this

group. However, the mean total score for the General Knowledge questions on the KA was moderately correlated with family income (rs[10] = .6, p = .06), but only approached statistical significance.

BPT group data (n = 9) were analyzed using Spearman's rank correlation tests of possible relationships between KA scores and family income was conducted. Only nine of the participants in the BPT group chose to report family income. None of the correlation tests showed statistically significant relationships between any of the KA items and family income.

The data for both the BPT and PE groups (n = 19) were then brought together in order to determine possible relationships between KA responses and family income variables regardless of group. Again, no statistically significant correlations were found for the responses to General Knowledge questions, responses to the Sleep Knowledge questions, or Generalization questions with family income. Table 11 provides correlations between family income and KA responses. Table 11

	BPT	BPT Group		roup	BPT + PE	
	п	rs	п	rs	п	r
Mean Score on General Knowledge Items	9	.08	10	.6	19	.36
Mean Score on Sleep Knowledge Items	9	.08	10	.36	19	.11
Mean Score on Generalization Items	9	38	10	.15	19	02
*** < 05						

Correlations between Family Income and Responses to the KA

**p* < .05

4.5 QUALITATIVE INTERVIEWS OF PARENT EXPERIENCE

What are parents' perspectives on the value of training in both groups (BPT and PE) 6-12 months following the end of intervention? The researcher used five questions to conduct brief 5-15 minute interviews (see Appendix E) with participants during the follow-up visit and transcribed audio recordings of these interviews into a qualitative computer package QSR NVIVO 10. Once the audio recordings were transcribed, the researcher used the techniques of narrative analysis (Coffey & Atkinson, 1996) and identified themes in participants' responses and placed statements into specific nodes. The two groups yielded twenty interviews, ten with the BPT group and ten with the PE group. Upon analysis of the interviews, six themes were identified within participants' responses: 1) discussion of children's current sleep behavior; 2) examples of current application of study materials; 3) general impact of the training; 4) critiques of the program; 5) other child characteristics; 6) other family characteristics.

4.5.1 Discussion of Children's Current Sleep Behavior

Although none of the interview questions specifically prompted parents to discuss their children's current sleep behavior, six parents (two of whom were in the BPT group and four from the PE group) spontaneously reported either continued improvements or persistent issues. There were two parents in the BPT group that reported that their children's sleep behavior improved following the training and that these changes continued to occur after training was complete. For instance, one of the parents (participant PT25) stated that her child was falling asleep at a "late hour, like 11:58 or 11:59 [pm]" at the beginning of the study and that after the study she began falling asleep at approximately 9 or 10 pm. This parent cited other reasons for her child's continued improvement at bedtime,

"I think maturity is happening. She's getting older and becoming part of us. Her sleeping patterns... she doesn't sleep as much as I want her to, but she's very calm about it. She's much more calm and compliant now and getting to be more independent. We've kind of got a new set of expectations and she's following it."

The other parent in the BPT group that reported on current sleep behavior (PT22), stated that some of the sleep improvements realized during the course of the training were no longer present and that the family had "*just started giving in to her*... *letting her sleep on the couch, but we kind of knew we were doing it. As long as she stays asleep through the night, we're okay with rolling with this. She does okay*... *so we're okay with it.*" This report indicates the parent had knowingly adjusted their expectation for sleep behavior and had accepted the consequences of this change.

Unlike the parents from the BPT group who discussed children's improved sleep behavior and their role in maintaining or not maintaining those improvements, the four participants from the PE group brought up their children's persistent disturbed sleep since completing the PE program. Three of these participants made general comments during the interview when they were asked to report on the helpful aspects of the PE training, participant PE06 stated that, "*[the PE program] did not really help with the sleep problems*", PE33 requested, "*now I would really like to schedule an appointment to train for the sleep problems*" and PE13 reported, "*the only thing I didn't like is you never talked about the sleep problems*." PE05 in the PE group reported that some of her child's sleep problems had abated without the application of any materials in the PE program. She stated that her son "*would just wake up constantly*" at the start of the PE program. Since the end of her participation in the PE program, she said there were improvements resulting from what she assumed to be, "*a combination of him* getting older and [behavioral health and rehabilitative services] therapy working, helping him to communicate more. It's been really helping his sleep. He's sleeping a lot better."

4.5.2 Examples of Current Application of Study Materials

When asked to provide examples of how parents had used the materials covered in the sessions, nine of the participants in the BPT group responded reporting specific behavioral recommendations to address sleep problems. PT08, PT10, PT14, and PT21 all reported changing their children's bedtime to a later hour as an application of bedtime fading that was presented in Session D of the BPT program. Other participants more generally discussed antecedent management strategies such as changing the time of a daytime nap or decreasing the duration of a nap (PT17, PT25, PT35) that was discussed in Session B of the BPT program. Additionally, there were some parents who reported completely altering evening activities to be more conducive to sleep, such as eliminating TV time at night (PT21), incorporating quiet activities (PT14, PT34), and changing the time of evening meals and snacks (PT21, PT34). Some participants also reported the use of a visual schedule to structure the bedtime routine (PT14, PT25). PT08 reported an antecedent strategy to decrease the disruption as a result of her child's night waking of "putting water beside the bed, that way she would just get a drink and fall back to sleep." PT22 and PT25 also reported placing a snack by children's beds so a snack would be available if an early morning waking occurred due to hunger.

The PE group participants were also asked about their use of the materials from the PE training and five participants responded noting examples of their application of these materials. PE05 reported using the materials discussing advocacy resources from Session D of the PE program to solve a problem with her son's school placement and she reported that she learned about,

"The different kinds of therapies and the different agencies, and how to get him signed up for medical assistance so it can all get paid for. And, getting him into the [specialized autism] program and, the big thing: the [specialized autism] program tried to screw us over actually, last year. And [the administrator for the specialized autism program] called me up a couple days before school was supposed to start and said, 'Oh, sorry, there's not space in it, in the three day class. He's getting moved to the two day class.' And I just, I had literally just started to be a parent advocate. I was able to talk to the educational lawyer and she told me exactly what to write down so they fixed it."

Similarly, PE30 reported utilizing the same advocacy materials to complete a modification in her child's Head Start program placement. PE05 and PE12 stated that the information on a local chapter of a national advocacy program (ABOARD) was used to access additional resources and assistance. PE28 reported that for her, the information on clinical evaluations and assessments from Session B was useful for her to use to prepare for an upcoming Individual Education Plan meeting she was preparing to attend on her child's behalf. Another parent, PE30, reported using the information obtained on the clinical evaluations to request additional score reports following her child's recent diagnostic visit to assess for attention-deficit/hyperactivity disorder. Finally, two PE group participants discussed application of information provided on evidence-based treatments for children with ASD from Session E. PE30 reported going online and searching for further information on social interaction therapies for her child using materials from this session. Similarly, PE 33 used additional materials from Session E to begin a video-modeling program for her child.

4.5.3 General Impact of the Training

When asked directly about perceptions on the impact of the training following their participation, four BPT participants responded with different information than was reported for other questions. PT10 suggested a general change in the manner she approached her child's sleep behaviors, stating surprise at the recommendation to push back her child's bedtime and the resulting improvement in his sleep,

"I really wouldn't have arranged his bedtime at first like that... [it] wasn't something we'd considered because... well, he needs to go to school so he needs to go to bed at this time. And just by learning to set the time back, just a little bit at a time, it actually helped a lot and it was an angle that we hadn't previously thought of..." When asked if that has changed the manner she uses to address her child's other behaviors, PT10 stated "Sometimes I think to myself, 'maybe there's another reason a certain problem is happening?' and I try to think about it in a clearer, more consistent way like how we changed his sleep."

PT18 reported a similar perspective on scheduling her child's activities, stating that she believed that examining her child's daytime schedule made her realize that starting activities sooner in the day and evening assists in calmer transitions and increased compliance from her child. Another parent, PT21 commented her general feeling following the BPT training,

"I think I got to see the role I have in his life. Like in teaching him things. I think before it was the therapists doing a lot of the work and I just copied them. But this sleep stuff, I feel like after those classes, I am an expert. I'm always telling my husband what to do and what not to do and why... it's just given me some area to control."

Finally, PT35 spoke about the impact she received as a result of the BPT training occurring very shortly after her young daughter was diagnosed with ASD,

"... I think it was good to talk with someone. She was just diagnosed, you know. So it was good to be sure we are doing everything we need to. No one can tell us we aren't trying everything for her."

The PE group participants responded more frequently with novel information when asked about the impact the PE sessions has had on their lives following their participation. Participants in the PE group whose children had recently been diagnosed with ASD at the time of their entry in the PE program reported more frequent and specific statements of the impact of the PE training. PE05 reported how the sessions allowed her to learn about,

"the different kinds of autism. We learned resources we could access, people we could talk to, and therapy we could find."

Likewise, PE06 reported,

"I think it's just empowered us kind of. Like we found an anchor and know where we're supposed to be and what we're supposed to be doing. Having all that help early on has given us time to fine-tune things and get things organized."

And PE23 stated,

"There's not... there weren't enough trainings actually to, you know, to try to be the better advocate for him and doing this, the sleep study, that was the first thing we did to try to help, you know, our son. And, during it, it was... it felt in the beginning like kind of nervous because it was right away after the diagnosis. But, well, definitely was so helpful and we felt that you know, we were trying to do the right thing for him and for us too because we needed to be informed so we can help him. If we're not informed, if we don't try to be, you know, better advocates, it's not going to work. So we have to be informed in order to help him. So definitely, yeah, it was good." PE 30 said,

"Just being able to identify the resources has helped to try to get everything under control. Having that information was really helpful overall and kind of helped me to feel like I had stuff together."

Whereas parents of children who were newly diagnosed reported a high impact following their participation in the PE program, parents of children who had been diagnosed for a year or longer prior to participating in the PE program responded differently to this question or stated that there was not an impact to report. PE29 stated,

"Okay. I guess I can't really think of anything. I mean, it helped to know we were on the right track. I guess in that way, it was like a verifying thing. Like verifying to us we knew what the right thing to do was. Does that make sense?... It made me feel like I knew what I was talking about when I talk about my son. When I think about him too. Like, I now know I understand what I need to know about him."

4.5.4 Critiques of the Program

Parents were asked which parts of the program they did not find helpful and several participants from the BPT group responded according to specific recommendations to address their children's sleep problems. PT08 reported that a recommendation to transition evening activities from the family's living room, to the bathroom (to have a bath and brush teeth), to the child's bedroom were not helpful due to the layout of the family's house. Additionally, PT08 reported the visual schedule was not helpful to teach her child to follow the schedule because she quickly lost the pictures. PT14 reported extensively about how her child did not seem to respond to any of the behavioral interventions recommended to her to address her son's night wakings,

"It just didn't work for us. I mean, for me to go back in and to give him a star when he's quiet... it was just crazy. I ended up having to go back in a zillion times and it kept me up all night, and it was confusing for him. I really felt what I was looking for was more of a help with what we can do to help him sleep fully through the night. It's not... it wasn't so much an issue of getting him to bed. He didn't tantrum or have a fit. He didn't have a lot of behavior problems going to sleep, it was just he woke up in the middle of the night and he would just be up, you know? So, you know basically that, and we have a lock on his door, we have a video camera. He wakes up, I can check on him on the video camera and he seems okay. I just let him hang... he just hangs out in his room. He doesn't scream, he doesn't and then he goes back to sleep."

This participant offered her own hypothetical explanation for her child's behavior,

"I feel like there's more of a medical or physical piece to this that I just don't have answers to. [BPT] didn't really make a huge... didn't make a whole impact. It would have if I'd never been introduced to the strategies with, you know, reinforcers and visual schedules and token board, but because we were already implementing that, it didn't make a whole lot of a difference."

PT18 reported that her child had a sleep association problem in that he required her to be present when he was falling asleep so that he could touch her hair. She reported that although his other sleep problems have since resolved, he did not respond to attempts to implement a stimulus fading technique because none of the substitutions (a baby doll, a large and heavy pillow) were sufficient for her child to transfer stimulus control.

The PE group was asked to report on aspects of the program they did not find helpful or would recommend changing and participants reported statements along one theme. Again, there

was a difference between PE participants whose children were recently diagnosed and PE participants whose children had been diagnosed for longer periods before starting the program. Participants whose children were newly diagnosed, such as PE05, PE06, PE30, each reported that the PE program applied to them directly at a time when they needed specific information about the diagnosis and services. However, participants whose children had already been diagnosed and who had already been through the process of completing evaluations, advocating for their children and accessing services reported that the information in the PE group frequently did not apply to them. PE12 reported simply that some of the information did not apply to her and her child. PE28 reported,

"I didn't want to go over some of the basic stuff. I just didn't need to know the really early things that would have been helpful for a parent just going through this. I think it would have been really helpful for me in the beginning."

Similarly, PE29 stated,

"I mean some of the sessions were really sad for me to hear. Like [my daughter] is pretty smart. I mean, I think she is. She's average in intelligence... I guess she just doesn't have... I mean to say she doesn't have the issues that a lot of other kids on the spectrum have. So, some of the stuff on the development really wasn't useful to us. We just don't and won't have certain issues because she talks pretty well and doesn't have a lot of problems like other kids. So I kind of wanted it to be more specific to her. Not to be rude, but I don't have a lot of time to be sitting there listening to stuff that isn't relatable to me."

PE33 commented,

"Since my son has had a lot of the services one tries to get when they're first diagnosed, I found some of the information was less relevant... or, applicable in my case. Had I met you all when he was first diagnosed, it would have been entirely helpful. So, I must say, sadly that the information on the assessments and advocacy was not the most helpful for me because I have already struggled through that."

Aside from all of the participants' recommended changes to the actual session materials, several parents from both groups recommended that the manner in which the training was delivered should be changed. Parents reported difficulty scheduling the appointments around other commitments (PE28, PT35), requesting that materials be posted online and sessions be conducted over the phone (PT10), or using Skype (PE28), and also decreasing the number of questionnaires and assessments required of participants (PE30).

4.5.5 Other Child Characteristics

During the course of the parent interviews, information was provided that did not immediately pertain to the questions presented to participants, yet may be helpful in determining characteristics about the children in this study that may or may not impact behavioral outcomes. For instance, from the BPT group, PT35 reported that her child was diagnosed with Fragile X syndrome following the screening/eligibility evaluation as a part of their participation in the RCT. Given that this parent participated in the BPT and was simultaneously receiving information and resources connecting her to the Fragile X research community, this may have impacted her experience both as a participant in the BPT program and her experience following her participation. PT35 stated an increased level of communication with service professionals involved in her son's life as a result of this second, genetic diagnosis,

"I constantly got people calling me or I've even talked to parents from ABOARD or even Family Care Connections. And they email me and Facebook me. And it's helpful to help other parents to support them."

Additionally, a participant in the PE group reported her son had recently received a diagnosis of attention-deficit/hyperactivity disorder in the months following her participation in the program. This second diagnosis stands to explain some aspects of the child's sleep and daytime behavior and these behaviors may be responsible for a difference in this particular family's perspective and experience following participation in the PE program.

4.5.6 Other Family Characteristics

One of the families in the BPT group, PT35, reported that both parents work full-time shift hours, on a schedule wherein the mother works daylight hours and the father works nighttime hours. A consistent overlap of approximately one hour occurs in the evenings before the father goes to work and in the mornings before the mother goes to work. As a result, this mother reported difficulty at times completing and staying consistent with her child's sleep intervention plan due to the inconsistency of the child's father's implementation of the daytime schedule. At time of follow-up, PT35 reported,

"My husband, her dad, he works nights and I work days. That was a big part of the problem with this sleep stuff. The kid didn't know what she was supposed to do, I guess. We are now separated, so it's harder to talk him into following the routine than it was before. But we're trying to keep her on track with the sleep stuff. She sleeps in the same house, we just come and go for now until she's older and one of us will move out."

It was helpful that this information was obtained as it may assist in explaining this particular child's sleep behavior and parent stress ratings at follow-up.

5.0 DISCUSSION

The purpose of this follow-up investigation was to examine the maintenance of outcomes and parent knowledge and generalization 6-12 months following parents' participation in a BPT to address children's sleep problems or a PE program as a part of a RCT and to assess for relationships between these variables. Although neither group showed significantly greater improvement than the other, the results shown at Week 8 of the RCT on children's sleep behavior and parental stress were maintained through follow-up. This study also found that parents who received BPT responded correctly more often to Sleep Knowledge items than the untrained PE group, which is consistent with past research assessing performance on a knowledge assessment post-training (Ingersoll & Dvortcsak, 2006; St. Lawrence, Hansen, & Steele, 1985). However, the PE group still performed well on the Sleep Knowledge subscale of the KA, indicating explicit training may not be necessary to perform well on this test.

After examining whether outcomes such as: children's sleep disturbances and parent stress, as well as demographic variables such as family income and parent education, were related to parents' performance on this knowledge assessment, two results were found. The BPT group's data showed a relationship between parents' ratings of stress and parents' correct responding to Sleep Knowledge items on the KA. Additionally, the untrained PE group showed a strong relationship between parents' ratings of stress and children's sleep disturbances. This result was predicted and echoes the results of numerous other studies (Doo & Wing, 2006; Hoffman et al., 2008; Richdale, 1999).

There were also correlations that approached significance, suggesting that with a larger sample these results may become more robust. First, when the data from the two groups were

combined, fathers' education level was moderately correlated with General Knowledge scores on the KA, but this correlation only approached statistical significance. The PE group's family income and General Knowledge KA scores were also analyzed and showed a moderate, positive correlation approaching statistical significance.

These findings raise three basic questions: (1) why did the PE group perform well on the Sleep Knowledge items of the KA despite not having received explicit training? (2) why were parents' scores on Sleep Knowledge items of the KA and children's sleep behavior not related? (3) why were children's sleep behavior ratings and parental knowledge about sleep behavior related to parent stress? A number of explanations will be considered.

5.1 WHY DID THE PE GROUP PERFORM WELL ON THE SLEEP KNOWLEDGE ITEMS OF THE KA DESPITE NOT HAVING RECEIVED EXPLICIT TRAINING?

Despite the BPT group's statistically significant superior scores on the Sleep Knowledge items of the KA, the PE group still scored well regardless of not having had explicit training in behavioral principles to address sleep problems. A possible explanation for this question has to do with the test items themselves. Parent knowledge was assessed through the analysis of parents' responses on a Knowledge Assessment (KA) which was designed using case vignettes from a BPT curriculum to address sleep problems in children with ASD. An analysis of the mean percentage scores for each session indicated that BPT Session A, which discussed the definition of behaviors and the antecedent, behavior, consequence model of behavioral intervention, yielded the PE group's highest score and differed to the BPT mean percentage score by only 12%. The high mean percentage of correct responses for this session's items may be due to the large proportion of parents whose children received BHRS and the common discussion of these concepts among BHRS providers. A greater difference between the two groups' scores was shown for the items representing material from sessions that discussed more specific behavioral concepts and strategies, in Sessions B, C, and D. The PE group demonstrated poorer performance in answering questions covering the more specific topics of antecedent strategies, extinction, reinforcement, bedtime fading, and treating sleep association problems through stimulus fading.

A second possible explanation for the PE group's performance on the Sleep Knowledge items has to do with participants' education levels. Upon examination of participants' education levels and their score on the KA, some trends were observed. First, the PE group was comprised of mothers who had a slightly higher range of education levels than the BPT group, showing a range of High School to Graduate and Professional education, compared to the BPT group's range of High School to College education levels. It is therefore possible that mothers in the PE group were able to respond correctly to the Sleep Knowledge items because they were more experienced at performing well on tests such as the KA. Once the questions on the KA became much more specific to behavioral procedures they had not had direct experience discussing (such as the topics discussed in Sessions B, C, and D of the Sleep Knowledge materials), mothers in the PE group responded less accurately to the questions than they had in the more general questions regarding material covered in Session A. It is therefore likely that parent education plays a role in parents' ability to perform well on this Knowledge Assessment, regardless of whether individuals received direct training.
An additional explanation to the PE group's performance was that the PE group was comprised of families with higher income than the BPT group. In fact, in an analysis of the mothers who performed at or above the mean on the Sleep Knowledge questions, half of the mothers reported high family incomes of above \$75,000 per year. The remaining mothers in the PE group who scored well on the Sleep Knowledge items were evenly distributed along the ranges of family income. This large proportion of mothers reporting high family income and also performing at or above the mean on the Sleep Knowledge items indicates that family income may be an additional factor in parents' performance on a Knowledge Assessment following behavioral training. Within the BPT group, similar trends of higher education and income were shown among high performers on the KA, but these were less robust.

Along the same vein, but involving General Knowledge questions, a moderate, positive, yet statistically insignificant, correlation between parents' income and PE group responses to the General Knowledge questions on the KA was found in this study. This result suggests that there may be a relationship between income and increased General Knowledge that is worth exploring in future studies with larger sample sizes. Despite the lack of information this provides about parents' application of behavioral principles to address target problems in children with ASD, this result may shed light on the type of parents who perform well at solving problems addressed in the General Knowledge items of the KA, which included: understanding children's ASD diagnoses, clinical assessments, developmental course of ASD, advocacy, and treatment planning. In other words, parents who were specifically taught to solve General Knowledge questions were more likely to perform better on these KA items if they had higher incomes. This may be due to parents with higher incomes using more services and gaining more knowledge in

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the process, allowing them to respond more accurately on a Knowledge Assessment covering these topics.

A fourth, but more tenuous, explanation for the PE group's performance on Sleep Knowledge items can be found in the combined data of the two groups when fathers' education level was assessed for relationships with the KA items. When the two groups' data were combined, fathers' education level showed a moderate and positive correlation with General Knowledge scores on the KA, but this correlation only approached statistical significance. Since the KA was completed almost exclusively by mothers (only one father completed the KA in the BPT group), this result is interesting because it indicates fathers' education may have an effect on mothers' responding to these items on the KA. Although, this may be a spurious relationship within this small sample, it is possible that one person in a household (in this case, the fathers of child participants) having a higher education level may have some effect on mothers' accurate responding to General Knowledge items on the KA regardless of explicit training in the General Knowledge material. Despite this result being found through the larger, combined group sample, rather than the PE group alone, the PE group showed slightly higher education levels reported for fathers than the BPT group. More research examining parental education level and performance on knowledge assessments following training is needed.

5.2 WHY WERE PARENTS' SCORES ON SLEEP KNOWLEDGE ITEMS OF THE KA AND CHILDREN'S SLEEP BEHAVIOR NOT RELATED?

Although, the results of this study demonstrated greater performance on the KA in the specially trained BPT group compared with the PE comparison group, further analyses did not show a

relationship between parents' responses to Sleep Behavior Knowledge items and children's sleep behavior. In fact, none of the sub-scores on the KA and children's sleep behavior on the MSPSQ were statistically significantly correlated. These results are not entirely surprising, given that children's sleep behavior between the two groups were not significantly different prior to assessing for correlation between the KA and children's sleep behavior.

One explanation for this lack of relationship is because although parents in the BPT group demonstrated superior Sleep Knowledge on the KA, the behavioral strategies that were implemented did not effectively address their children's sleep problems. A second possibility is that parents did not implement the strategies correctly. Finally, it is possible that parents implemented the strategies correctly and saw a change, but did not continue to implement these strategies over time. The qualitative interview data provided a rich background that assisted in more completely explaining parents' perspectives and experiences in the time since participation in either the BPT or PE training and the time when the follow-up visit occurred. On the whole, parents who completed the BPT program reported many examples of application of the materials covered in the sessions, and these highly corresponded with the recommendations that were provided to them during the program. Although a couple of parents alluded to the notion of using the BPT training to address other behavioral problems aside from sleep disturbances, none of the parents gave specific examples of having done so.

A direct observation measure of parental behavior when implementing interventions with their children might reveal more information about what is responsible for changes following a BPT program than data on parent knowledge alone. A strong relationship between knowledge gained and parents' actual implementation behaviors has been demonstrated in other studies. Stevens' (1984) study explored the relationship between parents' knowledge of normative

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development and parents' ability to design a home learning environment in 243 mothers of infants. Parents completed paper and pencil assessments of their knowledge of typical child development and were also observed using a structured observation and interview as they cared for their children in their home. When controlling for education and income, a strong, positive relationship between parent knowledge and parent behavior was shown between parent knowledge and behavior. A future study evaluating parent knowledge, parent behaviors when implementing intervention, and children's behavioral outcomes would provide greater understanding about the critical elements underlying BPT.

5.3 WHY WERE CHILDREN'S SLEEP BEHAVIOR RATINGS AND PARENTAL KNOWLEDGE ABOUT SLEEP BEHAVIOR RELATED TO PARENT STRESS?

As expected, there was a strong and statistically significant correlation between parents' ratings on the PSI and children's sleep behavior in the PE group. The high correlation between responses in the PE group on parental reports of stress and children's sleep behavior in this study mirrored that which has been reported in other studies. A study conducted in Hong Kong with 210 three to six-year-old children with Pervasive Developmental Disorders (PDD) and their families completed the PSI and a parent-completed sleep questionnaire, Children's Sleep Habits Questionnaire (CSHQ) (Doo & Wing, 2006). The results indicated a strong, positive correlation between children's increased sleep disturbance and parents' ratings of stress. This same relationship was shown in other studies with children with ASD conducted by Richdale (1999), and by Krakowiak and colleagues' (2008). When parent knowledge on the KA was assessed for relationships with parent ratings of stress on the PSI, only the BPT group's Sleep Knowledge responses on the KA were statistically significantly correlated with parent stress. This suggests that parents who responded more accurately to Sleep Knowledge items on the KA also tended to report higher levels of stress. Given that the BPT group showed similar ratings of children's sleep disturbances as the PE group, it is possible that parents who performed well on the Sleep Knowledge items on the KA were individuals who had attempted and been unsuccessful at solving sleep problems in their children and were experiencing continued, or greater, stress as a result. More research examining the role of parent knowledge of behavioral principles and parent stress is necessary in order to identify the role knowledge may play in affecting parent stress.

5.4 LIMITATIONS TO THIS STUDY

This study presented several limitations. First, the sample size was small and limited the representativeness of the sample as well as the ability to generalize findings. Second, the follow-up sample consisted of parents who elected to participate in this additional follow-up study. Therefore, there may be a self-selection bias. Given the young age of child participants and the time-frame of follow-up, maturation was an additional threat to the internal validity of the study, as reported improvements may have been a result of children's natural development and not necessarily parents' participation in the study. Similarly, history posed a threat to internal validity given that a variety of events may have occurred to affect children's sleep behavior or parents' responses to assessments of knowledge or reporting of stress between participants' completion of the study and the follow-up period. Attrition served to be the most major threat to

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internal validity due to the long period of follow-up and less incentive to participate posttreatment.

Additionally, the lack of variability within the subscales in the KA measure was an inherent limitation of this follow-up study. This may have resulted in an insufficient number of activities to measure knowledge of the various behavioral principles and limit parents' demonstration of knowledge. Finally, because an assessment of parent knowledge or generalization was not conducted at the termination of the program, it was not possible to compare time-points within groups at the end of the study and follow-up. Therefore, assessment of maintenance of knowledge and generalization was compared between the group that received treatment (BPT) and the group that did not receive treatment specific to sleep problems (PE).

5.5 IMPLICATIONS FOR FUTURE RESEARCH

Future research on the potential variables critical for the efficacy of BPT, such as parent knowledge, parent behaviors during implementation, and child outcomes need to be assessed with a larger sample than the one used for this study. Although the results of this study did not reveal many statistically significant results regarding the difference in parent knowledge between the two groups, it is possible that a larger sample would have demonstrated these results more clearly with greater statistical power. Similarly, the relationships between parent knowledge and ratings of children's sleep behavior and parent stress may have been stronger, had the sample size been larger. Therefore, future follow-up studies within trials of BPT assessing parent knowledge may shed more light on these variables.

Additionally, future assessments of parent knowledge might include a greater number of time-points when parent knowledge is assessed, such as pre-training and at a time-point during training, as opposed to only at a post-training time-point. Multiple time-points would afford the opportunity to assess changes in parents' application of behavioral concepts when given hypothetical case vignettes over time. These additional datum points would allow also for a clearer assessment of any relationships that may exist between parent knowledge and children's behavioral outcomes prior to and during the BPT training.

Last, further research assessing parents' behaviors concurrent with parent knowledge will assist in better clarity about the relationship between what parents *know* and what *behaviors they perform* when actually intervening with their children's behavior problems. A well-controlled evaluation of a BPT program including both of those measurements will lend greater understanding about what occurs following BPT that only involves in-clinic didactic training of behavioral concepts that leads to child outcomes. More research evaluating these critical aspects of BPT programs is necessary.

During the qualitative interviewing portion of this study, participants in both groups cited the inconvenience of coming into an urban clinic for each session to be a taxing event. It is possible that once this BPT program to address sleep problems is validated, the delivery of this standardized program may become more accessible using tools of telemedicine. The parents' suggestions to utilize more innovative technology in the delivery of parent training echoed what has been an area of burgeoning research. A web-based delivery mechanism of parent training was recently evaluated in a small study for feasibility in the delivery of speech language pathology treatment. Baharav and colleagues (2010) assessed two types of mechanisms to deliver a parent training program to two parents of 4-5 year-old children with ASD. Outcomes

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following a traditional twice weekly speech language pathology clinic visit were compared to that of a clinic/telepractice model that consisted of only one weekly clinic visit and one weekly remote internet communication via webcam from families' homes. Results of this study showed that both parents rated the experience in both treatments as equally valuable and that the remote consultation resulted in equal progress for children as the twice weekly clinic visits. Given the strain on families to coordinate and spend time attending clinic visits for children with ASD to receive treatment, this new research provides promising evidence of a way for BPT to become an even more feasible mechanism for service delivery.

APPENDIX A

FIGURE I. Summary	of Literature on	Treatment with	Standard Extinction

Reference	Setting/ Subject	Target Behavior	Baseline	Assessment	Treatment Protocol	Design	Comparison group (s)	Follow -up	Results
Williams (1958)	n = 1F 21 mos TD	Bedtime crying	None	Diary	Ext	Case history	None	2 yrs	Effective reducing crying duration at bedtime
Wolf et al., (1964)	n = 1M 3.5 yrs ASD	Night waking; severe tantrums	None	Direct obs; cumulative record	Ext & mild punishment	Case study	None	6 mos	Initial increase in problem behavior; night waking eliminated by 6 th night; maintained at follow-up
Rapoff et al. (1982)	n = 6 24-54 mos TD	Bedtime	6-10 days	Audiotape	Ext & mild punishment	Mult. baseline across subjects		6 mos	Effective for all problem sleepers (50% of sample)
Seymour et al. (1983)	n = 208 0-6 yrs TD	Night waking	4-7 days	Diary; parent report	Bedtime routine; ext	Within subject	None	6 mos	Effective reducing night wakings for 78% of subjects; attrition
Chadez & Nurius (1987)	n = 1F 7 mos TD	Night waking	6 days	Diary; parent report	Ext with and without cognitive	ABAB design		47 days	Effective only with cognitive restructu- ring for parents

restructu-

ring

Rickert & Johnson (1988)	n = 33 6-54 mos 18m, 15f TD	Night waking	1 week	Diary	Ext or scheduled waking	Between group; random- ized	Control; scheduled awakening	6 wks	Ext = scheduled waking > control; faster results with ext
Seymour et al. (1989)	n = 45 9-60 mos 28m, 17f TD	Bedtime; night waking	None	Diary; questionnai re	Written instruction (booklet); therapist guidance	Between group; random- ized	Wait-list control	3 mos	Booklet = therapist- guided > control
France & Hudson (1990)	n = 7 8-20 mos 5m, 2f TD	Night waking	1-8 wks	Diary; questionnai re recording	Ext	Non- concur- rent mult. baseline		3 mos; 2 yrs	Effective for night waking

Reference	Setting/Subject	Target Behavior	Baseline	Assessment	Treatment Protocol	Design	Comparison group (s)	Follow -up	Results
Rolider & Van Houten (1984)	n = 3 24-30 mos 3M TD	Bedtime	5-15 days	Diary	Grad ext	Mult. baseline across children		70 days	Effective for bedtime; not traditional grad. ext.
Pritchard & Appleton (1988)	n = 31 9-42 mos 19M, 12F TD	Bedtime; night waking	6 days	Diary	Grad ext; bedtime routine	Between group	Quasi- control	3 mos	Dec. in bedtime problems and night waking
Adams & Rickert (1989)	n = 36 18-48 mos 16M, 20F TD	Bedtime	7 wks	Diary; reliability chk	Grad ext	Between group; randomized	Control; positive routine	6 wks	Grad ext = pos. routine; checking more difficult for parents
Durand & Mindell (1990)	n = 1F 14 mos TD	Bedtime; night waking	3 wks	Diary; videotape	Grad ext	Mult. baseline across behavior		9 mos	Checking effective for both bedtime and night waking
Lawton et al. (1991)	n = 6 6-14 mos 2M, 4F TD	Bedtime; night waking	2-5 wks	Diary; reliability chk	Grad ext	Mult. Baseline		4 mos	Improve- ments in 4/6 children; dec ext burst
Mindell	n = 6	Night	2-4 wks	Diary;	Grad ext	Mult.		1 mo	Checking

FIGURE II. Summary of Literature on Treatment with Graduated Extinction

& Durand (1993)	18-52 mos 4M, 2F TD	waking		videotape		baseline/ simultaneou s replication			technique at bedtime; treatment at bedtime generalized to night wakings
Sadeh (1994)	n = 50 9-24 mos 28M, 22F TD	Night waking	1 wk	Diary; actigraph	Grad ext	Between group; randomized	Parent cosleeping in room (no attn)	3 wks	Checking technique effective = parent cosleeping
Durand et al. (1996)	n = 4 2 & 12 yrs 1M, 1F 2 ASD (plus 2 with other diagnoses)	Frequent bedtime disturbances; sleep latency	4 - 16 days	Diary	Grad ext	Multiple baseline across subjects		None	Reduction in sleep disturbances in both children; improved sleep latency in one child

Reference	Setting/Subject	Target Behavior	Baseline	Assessment	Treatment Protocol	Design	Comparison group (s)	Follow- up	Results
Milan et al. (1981)	n = 3 2-15 yrs 2M, 1F DD	Bedtime	5 days	Diary; reliability chk	Bedtime fading & routine	ABC replication	None	1-2 yrs	Rapid & effective at reducing tantrums; severely handicapped population
Adams & Rickert (1989)	n = 36 18-48 mos 16M, 20F TD	Bedtime	7 wks	Diary; reliability chk	Bedtime fading & routine	Between group; randomized	Control; grad ext	6 wks	Equal to grad ext; grad ext more difficult for parents
Piazza et al. (1997)	n = 14 4-14 yrs 5 ASD, 1 PDD, 9 DD	Bedtime; delayed sleep; night/ early waking	Unclear duration	Diary; partial interval recording system	Bedtime fading & response cost (FBRC)	Between group; randomized	Bedtime scheduling	None	Reduction in mean hours disturbed sleep in FBRC group
Piazza et al. (1998)	n = 1F 8 yrs ASD, severe DD, congenital	Disrupted sleep- wake schedule	14 days	Momentary time sampling procedure: 30 minute intervals, 24	Bedtime fading	Case study		4 mos	Decrease in sleep latency and night waking,

FIGURE III. Summary of Literature on Treatment with Bedtime Fading

	omphalocele			hours/day				increase in total sleep time; gains maintained at follow-up
DeLeon et al. (2004)	n = 1M 4 yrs Severe SIB ASD	SIB associated with night waking	42 days	Direct observation using scheduled wakings to assess post- waking SIB	Bedtime fading (in an inpatient unit)	Case study	 None	Reduction in night wakings and SIB
Moon et al. (2010)	n = 3 2M, 1F ASD, Avg. IQ 8-9 yrs	Significant difficulty initiating sleep	7 days	Diary, actigraphy, sleep and daytime behavior parent- completed questionnaires	Bedtime fading with response cost	Case-series	12 wks	Reduction in sleep latency for all; maintained at follow- up; small decrease in daytime behaviors; parents satisfied with results

Reference Howlin (1984)	Setting/Subject n = 1M 5.5 yrs ASD	<i>Target</i> <i>Behavior</i> Sleep onset problems, night waking, co- sleeping	Baseline 2 wks	Assessment Direct observation by parent	Treatment Protocol Stimulus fading	Design Case study	Comparison group (s)	Follow- up 3 mos	<i>Results</i> Child settled within few minutes, no attempts to return to parents' bed, decrease in night waking
Christodulu & Durand (2004)	n = 4 2-5 yrs 2M, 2F 1 ASD, 3 DD	Bedtime; night waking; co- sleeping	9-14 days	Diary; questionnaires	Sleep restriction protocol & bedtime routine	Mult. baseline		None	Improved consolidation of sleep; duration of sleep decreased for 3 participants
Durand & Christodulu (2004)	n = 2F 4 yrs 1 ASD, 1 DD	Bedtime; night waking; sleep assoc.; sleep- walking; sleep terrors	6-11 days	Diary; questionnaires	Sleep restriction protocol	Mult. baseline		None	Significant reduction in all target sleep problems

FIGURE IV. Summary of Literature on Treatment of Stimulus Control / Sleep Association Problems

Reference Wiggs & Stores (1998)	Setting/Subject n = 30 8-10 yrs 18M, 12F severe LD	Target Behavior Settling problems; night/early waking	<i>Baseline</i> Unclear duration	Assessment Functional analysis; questionn- aires; activity monitor	Treatment Protocol 6 sessions individual BPT	Design Between group; random- ized	<i>Comparison</i> <i>group</i> (<i>s</i>) Control	Follow- up	Results Reduction in target behaviors
Moore (2004)	n = 1M 4 yrs ASD, Severe LD, rec. lang. delay	Sleep onset problems, night waking, early waking, co- sleeping	Unclear if baseline data were collected	Parent report of sleep problems, questionnaire to assess behavioral function, social validity interview with mother	Multiple components: grad ext, social story, token economy, bedtime routine	Case study			Sleep latency and co- sleeping decreased, after 1 st day, child accepted sleeping in own bed, only slept in mother's bed twice during treatment
Montgomery et al. (2004)	n = 66 2-8 yrs 42M, 24F 21 ASD, 45 LD	Bedtime; night waking	2 wks	Diary; question- aires	1 session BPT by booklet	Between group; random- ized	Booklet only; crossover control	6 mos	Effective; face-to- face equal to booklet > control

FIGURE V. Summary of Literature on Multicomponent Behavioral Parent Training (BPT) Programs

Weiskop et al. (2005)	n = 6 1-9 yrs 10M, 3 F ASD / Fragile X	Bedtime; night waking; co- sleeping	3-5 wks	Diary; goal question- aire; social validity	3 sessions individual BPT sessions	Concur- rent mult. baseline	 3 mos; 12 mos	Significant reductions in target behaviors
Reed et al. (2009)	n = 20 5-7 yrs 16M, 4F ASD	Bedtime; night/early waking;	Unclear duration	Questionn- aires; actigraphy	3 sessions; 3-5 families group workshop; BPT	Within	 None	Improve- ment in majority of group

APPENDIX B

Knowledge Assessment (KA)

BPT Session A:

1. Please read each of the words below and circle the ones that are <u>behavioral</u>:

Nice	Тар
Annoying	Kick
Spit	Mean
Bite	Read
Sweet	Uncooperative
Bang	Good
Gentle	Wink
Rough	Lick
Sniff	Poke
Hover	Turn

2. Please read the following scenario and answer the questions that follow:

Mary often screams, hits, and kicks her grandmother when she is told it is time to take a bath and get into bed. When this happens, Mary's grandmother allows her to take a bath the next morning instead.

- a. Please identify the **<u>behavior</u>** in this scenario:
 - i. Mary screams, hits, and kicks.
 - ii. Mary's grandmother allows her take a bath the next morning instead.
 - iii. Mary is told to get a bath and go to bed.
- a. Please identify the *antecedent* in this scenario:
 - i. Mary screams, hits, and kicks.
 - ii. Mary is told to get a bath and go to bed.
 - iii. Mary's grandmother allows her take a bath the next morning instead.
- b. Please identify the <u>consequence</u> in this scenario:

- i. Mary is told to get a bath and go to bed.
- ii. Mary's grandmother allows her take a bath the next morning instead.
- iii. Mary screams, hits, and kicks.
- 3. Please read the following scenario and answer the questions that follow:

After Markell falls asleep in his parents' bed, his father moves him into his own bed. Then, Markell usually wakes up and begins to cry. Once Markell starts to cry, his father allows him to return to his parents' bed to sleep for the rest of the night.

- b. Please identify the **<u>behavior</u>** in this scenario:
 - i. Markell's father moves him into his own bed.
 - ii. Markell wakes up and cries.
 - iii. Markell's father allows him to sleep in his parents' bed.
- c. Please identify the **antecedent** in this scenario:
 - i. Markell's father allows him to sleep in his parents' bed.
 - ii. Markell's father moves him into his own bed.
 - iii. Markell wakes up and cries.
- d. Please identify the <u>consequence</u> in this scenario:
 - i. Markell wakes up and cries.
 - ii. Markell's father moves him into his own bed.
 - iii. Markell's father allows him to sleep in his parents' bed.
- 4. Please watch the following *video vignette* and answer the questions that follow:

After his mother says "good night" and turns out the light, Markell begins banging his head against his headboard. When his mother hears him banging, she returns to his room, turns on the light and rocks in a rocking chair with him until he falls asleep.

- a. Please identify the **<u>behavior</u>** in this scenario:
 - i. Markell's mother says "good night" and turns out the light.
 - ii. Markell bangs his head on his headboard.
 - iii. Markell's mother returns and rocks him until he falls back asleep.
- b. Please identify the **antecedent** in this scenario:

i. Markell's mother says "good night" and turns out the light.

- ii. Markell bangs his head on his headboard.
- iii. Markell's mother returns and rocks him until he falls back asleep.

- c. Please identify the <u>consequence</u> in this scenario:
 - i. Markell's mother says "good night" and turns out the light.
 - ii. Markell bangs his head on his headboard.
 - iii. Markell's mother returns and rocks him until he falls back asleep.
- 5. Please watch the following *video vignette* and answer the questions that follow:

Mary watches 1 hour of television before she is asked to get into bed. Once her mother turns off the television, Mary has a tantrum. Mary cries so loudly that her mother allows her to stay up and watch television until she falls asleep on the couch.

- d. Please identify the **<u>behavior</u>** in this scenario:
 - i. Mary's mother turns off the television.
 - ii. Mary's mother allows her to continue watching television and fall asleep on the couch.
 - iii. Mary has a tantrum.
- e. Please identify the **antecedent** in this scenario:
 - i. Mary's mother turns off the television.
 - ii. Mary has a tantrum.
 - iii. Mary's mother allows her to continue watching television and fall asleep on the couch.
- f. Please identify the <u>consequence</u> in this scenario:
 - i. Mary's mother allows her to continue watching television and fall asleep on the couch.
 - ii. Mary has a tantrum.
 - iii. Mary's mother turns off the television.

BPT Session B:

6. Please watch the following *video vignette* and identify a strategy that would help this parent prevent the child's sleep problem from occurring.

Markell's favorite uncle stops by to visit him right before bedtime. Markell jumps up and down and begins to run around the house screaming with excitement. After his uncle leaves, Markell's mother tries to calm him down to get ready for bed.

- a. Change setting events
- b. Use visual or auditory cues

c. Avoid certain settings or people at naptime or bedtime

- d. Change how you ask or respond to the child
- 7. Please watch the following *video vignette* and identify a strategy that would help this parent prevent the child's sleep problem from occurring.

Mary is playing quietly in her bedroom. Her mother walks into her room and tells her it is time to go to bed. When Mary says "no" her mother yells at Mary and tells her it's time for bed. Mary begins to cry and tantrum.

- a. Change how you ask or respond to the child
- b. Change order of events
- c. Avoid certain settings or people at naptime or bedtime
- d. Control the environment by minimizing loud sounds
- 8. Please watch the following *video vignette* and identify a strategy that would help this parent prevent the child's sleep problem from occurring.

Markell really enjoys brushing his teeth but really dislikes putting on his pajamas. Markell's father asks him to put on his pajamas and Markell begins to cry and hit his father. Markell refuses to change his clothes and continues to cry until he is put in bed without changing clothes.

- a. Use visual or auditory cues
- b. Change setting events
- c. Control the environment by adjusting the temperature in the house

d. Change order of events

9. Please watch the following *video vignette* and identify a strategy that would help this parent prevent the child's sleep problem from occurring.

Mary's parents have successfully been able to have her fall asleep at a reasonable hour and sleep through the night. However, Mary still wakes up every morning around 5:30am when the sun rises and brightens her room.

- a. Change setting events
- b. Control the environment with dark blinds/curtains on the window
- c. Change order of events
- d. Avoid certain settings or people at naptime or bedtime
- 10. Please watch the following *video vignette* and identify a strategy that would help this parent prevent the child's sleep problem from occurring.

Markell wakes up every night at 2am and requests a snack and a drink of water. Once his mother gives him his food and drink, he voluntarily returns to bed and falls asleep quickly.

a. Change setting events

- b. Avoid certain settings or people at naptime or bedtime
- c. Change order of events
- d. Use visual or auditory cues

BPT Session C:

11. Please watch the following *video vignette* and identify which step was <u>not</u> used to <u>reinforce</u> the child's behavior:

Markell's father is using a visual schedule with him to follow a bedtime routine. After completing all three steps of the schedule, his father tells Markell that he will get to have a special toy after school <u>the following day</u>.

- a. Keep the behavioral requirement reasonable
- b. Be sure that reinforcers are initially given closely following the behavior
- c. Consider using visual reminders of the reinforcer
- 12. Please watch the following *video vignette* and identify which step was <u>not</u> used in the <u>reinforcement</u> of the child's behavior:

Mary's mother is trying to teach her to follow a new bedtime routine. Mary's mother is giving her a small piece of candy each time she completes 2 steps on the schedule. When Mary refuses to take a bath, Mary's mother still gives her a piece of candy and allows her to skip that step to move onto the next activity.

- a. Consider using visual reminders of the reinforcer
- b. Keep the behavioral requirement reasonable
- c. Be sure to use reinforcers contingently (only when behavior occurs)
- 13. Please watch the following *video vignette* and identify which step was <u>not</u> used in the extinction of the child's behavior:

Markell tantrums when he is asked to put on his pajamas. His mother stops talking to him and turns her body away. Once Markell begins to hit her legs, she looks down at him in disapproval.

- a. Do not touch the child; walk away if necessary
- b. Do not talk to the child or respond to him/her
- c. Make ignoring obvious, abrupt and exaggerated
- d. Avoid eye contact; do not look at the child

14. Please watch the following *video vignette* and identify which step was <u>not</u> used in the extinction of the child's behavior:

Mary wakes in the night and screams out for her mother. Mary's mother enters her bedroom and holds, rocks, and sings to Mary.

- a. Do not touch the child; walk away if necessary
- b. Do not talk to the child or respond to him/her
- c. Make ignoring obvious, abrupt and exaggerated
- d. Avoid eye contact; do not look at the child
- 15. Please watch the following *video vignette* and identify which step was <u>not</u> used in the extinction of the child's behavior:

Markell's mother tucks him into bed and Markell asks his mother for one last drink of water. When his mother tells him "no" and turns to leave, Markell asks his mother "Why not?" Markell's mother then continues to have a conversation with Markell about why he cannot have another glass of water. Markell repeatedly asks her "But, why?" which continues to delay bedtime.

- a. Do not touch the child; walk away if necessary
- b. Do not talk to the child or respond to him/her
- c. Make ignoring obvious, abrupt and exaggerated
- d. Avoid eye contact; do not look at the child

BPT Session D:

- 16. Markell's parents have been using a consistent bedtime routine and place him in bed by 8pm. However, Markell is not falling asleep until well after 10pm. During that time when he is supposed to be asleep, he plays with toys in his bed and cries for his parents to read stories to him. *What could Markell's parents do to have Markell fall asleep closer to the time when he is put in bed?*
 - a. Markell's parents could encourage him to fall asleep on the couch in the living room whenever he is tired and move him into his own bed after he is asleep.
 - b. Markell's parents could reinforce him with special candy for going to sleep at an earlier time. They could use picture icons to indicate which candies he will receive for sleeping in his own bed.
 - c. Markell's parents could make his bedtime 10pm until he begins to fall asleep within 20 minutes of being put in bed. As he sleep consistently in his bed, they could slowly move his bedtime to an earlier hour.
 - d. Markell's parents could simply have Markell stay up as late as he wants in his room and let him play until he falls asleep on his own.
- 17. Mary's parents keep a consistent bedtime routine and have her in bed by 8pm every night. Yet Mary consistently wakes up several times at 11pm and 4am for at least 2 hours

each time and finally wakes at 10am for the day. What would you suggest Mary's parents do to help Mary sleep for one long period in the night rather than many small periods?

- a. Mary's parents could delay her bedtime so she is falling asleep later and wake her up earlier than 10am so she will begin to sleep through the night for an initial goal of 6-8 hours of uninterrupted sleep.
- b. Mary's parents could keep the current schedule, but ignore her crying in the night. Over time, Mary will learn that her parents will not come in to check on her if she cries.
- c. Mary's parents could put a lock on her bedroom door so she will be safe and not wander around at night when she wakes up. Over time, she will stop waking up to obtain attention.
- d. Mary's parents could reward Mary for staying in her room from 8pm to 10am every night by allowing her to watch her favorite television shows during the day.
- 18. Markell takes 5-6 brief (30-45 minute) naps during the day. He is having trouble falling asleep before 1am and will only sleep until 5am. What would you suggest <u>as the first step</u> to help Markell get on a better sleep schedule where he is falling asleep and waking up at a reasonable hour?
 - a. Right away, his parents could take away all opportunities for Markell to take any naps. They should keep him busy with activities to keep him awake all day no matter how much he tantrums because he is over-tired.
 - b. His parents could gradually try to decrease the number of naps Markell takes during the day over time. If they change his schedule too quickly, Markell could resist and have more sleep problems.
 - c. His parents could put him to sleep at a later time since he is clearly going to be sleeping during the day anyway.
 - d. His parents could reinforce Markell with more video games for staying awake during the day and falling asleep when he should.
- 19. In order for Mary to fall asleep her mother needs to rock her in the living room recliner with a game show playing on the TV in the background. After she falls asleep, Mary's mother will transfer her to her bed but Mary often wakes up during this time and needs to return to the recliner to help her back to sleep. What would you suggest her mother do to have Mary begin to fall asleep in her bedroom instead of the living room?
 - a. Mary's mother could just put Mary in bed and tell her that the new rule is that she fall asleep on her own.
 - b. Mary's mother could begin by creating a visual schedule that shows Mary the steps of the new bedtime routine.
 - c. Mary's father could begin putting Mary to bed and use a new routine.
 - d. Mary's mother could begin by rocking Mary in her bedroom instead of the living room.

- 20. Markell will only fall asleep if he lies in a big pile of pillows on the floor of his room with the family dog. In the middle of the night, the dog will bark, wanting to go outside. Markell then wakes and cries until the dog returns. What would you suggest his parents do to have Markell sleep in his own bed without the dog?
 - a. Markell's parents could put all of the pillows in his bed and give him a stuffed toy dog for him to hold while in bed.
 - b. Markell's parents could hide all of the pillows and put the dog in another room so he cannot fall asleep anywhere but his bed.
 - c. Markell's parents could temporarily have him sleep in their bed with the dog and then transfer him to his own bed when he falls asleep.
 - d. Markell's parents could create a visual aid to show Markell where he should be sleeping.

PE Session B

Please read the text box below and answer questions 21-23.

Mary is four years old and is able to say 5 words that are clearly understood. When she is unable to communicate her wants and needs, Mary cries and throws tantrums. Otherwise, Mary is relatively calm and does not display very many challenging behaviors. She enjoys a variety of foods and likes to play with many different toys. Mary cries when she is in crowds of people and avoids playing with other children at preschool unless she is prompted to participate.

- 21. What do you think are Mary's greatest strengths in her development?
 - a) Mary's greatest strengths are that she is relatively calm, does not display challenging behaviors, and avoids playing with other children at preschool.
 - b) Mary's greatest strengths are that she does not display very many challenging behaviors, she has extensive communication ability for her age, and that she likes a variety of food and toys that can be used for reinforcement.
 - c) Mary's greatest strengths are that she likes a variety of food and toys that can be used for reinforcement, she is calm, and does not display very many challenging behaviors.
 - d) Mary's greatest strengths are that the 5 words she says are clearly understood, that she is not aggressive, and that she avoids playing with other children at preschool (instead of crying).
- 22. What do you think are Mary's greatest challenges in her development?
 - a) Mary's greatest challenges are that she only says a small number of words, she cries and tantrums when she is not understood, and she is avoidant of other children at preschool.
 - b) Mary's greatest challenges are that she is avoidant of other children at preschool, only tantrums when she is not understood, and cries when she is in crowds of people.

- c) Mary's greatest challenges are that she likes a variety of foods and toys, she is relatively calm, and only says a small number of words.
- d) Mary's greatest challenges are that she cries when she is in crowds of people, she likes a variety of foods and toys, and she is avoidant of other children at school.
- 23. What issue is most concerning about Mary's development?

a) Mary's communication development.

- b) Mary's tantrums.
- c) Mary's social development.
- d) Mary's repetitive behaviors.

Please read the text box below and answer questions 24-25.

Markell is three years old and is able to vocally request up to 100 items and activities independently. He displays echolalia and repeats scripts of TV shows and movies frequently. Markell likes to follow a very specific routine and is best described as "inflexible and rigid." He tantrums for long periods of time (lasting more than one hour) at least three times each day when things do not go his way. He is interested in playing with other children at preschool but tantrums when they disrupt his play routines.

24. What do you think are Markell's greatest strengths in his development?

- a) Markell's greatest strengths are his communication development and his ability to follow routines.
- b) Markell's greatest strengths are his ability to follow routines and that his tantrums are relatively brief.
- c) Markell's greatest strengths are his interest in playing with other children at preschool and his extensive memory for TV and movie scripts.
- d) Markell's greatest strengths are his communication development and his interest in playing with other children at preschool.
- 25. What do you think are Markell's greatest challenges in his development?
 - a) Markell's greatest challenges are his inflexibility and rigidness as well as his deficit in communication.
 - b) Markell's greatest challenges are his interest in playing with other children at preschool and his echolalia.
 - c) Markell's greatest challenges are his inflexibility and rigidness as well as his repeating of TV and movie scripts.
 - d) Markell's greatest challenges are his repeating of TV and movie scripts and his deficit in communication.

PE Session C

26. During which developmental period do you think Mary's parents should have <u>first</u> been concerned about her lack of responsiveness to others, lack of joint attention and eye contact, and lack of spoken words?

a) During Mary's early childhood and preschool years (birth-5 years).

b) During Mary's adulthood (18 years +).

c) During Mary's adolescence (11-17 years).

27. During which developmental period do you think Markell's parents should have been **most** concerned about his lack of understanding of financial responsibility and social and legal obligations?

a) During Markell's adolescence (11-17 years).

b) During Markell's middle childhood years (5-10 years).

c) During Markell's adulthood (18+ years).

28. Markell is currently an adolescent and is very much motivated to have friends, go to parties, and hang out with them on the weekends. Despite knowing a lot of the students at his school, Markell seems to be much more immature than they are. He is teased and sometimes even bullied on the bus and during homeroom but does not seem to recognize that these bullies are not his friends. *What could Markell's parents do to intervene to help him make friends and avoid negative situations?*

- a) Markell's parents could send him to a social skills group and create a goal on his treatment plan that aims to address reading social cues and social problem solving.
- b) Markell's parents could contact his school and ensure that all teachers and students are aware of Markell's social deficits to attempt to foster a more accepting environment.
- c) Markell's parents could involve him in more community activities where he could practice dealing with more age-appropriate interactions.
- d) All of the above.

29. Mary is currently seven years old and despite being fully included in her second grade classroom, she is struggling to follow directions and participate in all activities without having tantrums. Her classroom is somewhat chaotic and the schedule changes almost daily due to turnover of teacher's aides. *What could Mary's parents suggest her teacher do to help include her more in all classroom activities?*

- a) Mary's parents could suggest her teacher use time-out to have her comply with all activities.
- b) Mary's parents could change Mary's school in order to get a fresh start so Mary can best succeed.
- c) Mary's parents could suggest her teacher implement a structured routine so Mary can predict what will happen each day.

d) All of the above.

30. Markell is 14 months old. He does not yet speak, avoids eye contact and carries around a coat hanger and dish towel wherever he goes. He flaps his hands and tenses his body when he is excited. He tantrums when his routine is not followed. Markell's parents are concerned he might have autism but are unsure of what to do about it. What would you suggest Markell's parents do to address these issues?

- a) His parent should wait until he grows out of it. There is a small minority of children who show these behaviors and eventually begin to develop more typically.
- b) His parents should raise these concerns with Markell's pediatrician immediately in order to get a referral for an assessment of these issues.
- c) His parents should get a referral from their pediatrician and get a specialized assessment but not seek intervention in the home since he will get treatment at preschool when he turns 3 years old.
- d) His parents should read as much as possible about autism and attempt to treat him at home themselves so he will begin responding to them immediately.

PE Session D

31. Markell's parents are in need of some financial assistance to send him to swimming lessons specifically for children with special needs. *Which advocacy resource would be helpful to contact to <u>most directly meet this need?</u>*

- a) An educational lawyer
- b) A parent support network
- c) A public grant program which parents can apply for financial assistance for children with special needs
- d) Family members who could pay for extra assistance

32. Mary's parents are really concerned about the appropriateness of her classroom placement and educational program. They have met with her teacher and other school personnel and feel that her needs will not be met in that environment even if the school keeps their promises to change the program to fit Mary's needs. The school has denied requests to complete specific assessments and has stopped responding to Mary's parents' requests to continue to meet to discuss her progress. *Which advocacy resource would be helpful to <u>most directly meet the need of finding out more information about legal options?*</u>

- a) A public grant program which parents can apply for financial assistance for children with special needs
- b) A parent support network to talk with parents about the child's diagnosis
- c) The principal of Mary's school
- d) An educational lawyer who represents parents of children with autism who have concerns about their child's school placements

33. Markell is in elementary school and is doing very well academically. His parents are concerned because although Markell is very bright and will likely continue to perform well in his classes, his independent functioning will continue to need improvement. For instance, Markell is able to complete all of his higher-level assignments but struggles to prioritize his assignments, manage his time, and maintain his concentration without constant prompting. *Which advocacy resource would be helpful to <u>most directly</u> meet the need of helping Markell to learn these skills to work more independently?*

- a) An educational lawyer
- b) A mentor program for students with ASD
- c) A parent support network
- d) Markell's high school teachers

34. Mary receives home based therapy. However, the one-on-one therapists seem to be addressing her behaviors in different ways when they are with her. The consultant has not spent very much time assessing Mary's behaviors and has not observed the two different therapists. Mary's father does not want to "rock the boat" by asking the therapy team to do more to assist Mary, but her mother is fed up with the lack of consistency. *What should Mary's parents do to advocate for improvement in Mary's treatment?*

- a) Mary's parents should call the therapy agency and request a new consultant and new one-on-one staff-member(s). Clearly these individuals are not working well with Mary and need to be replaced.
- b) Mary's parents should call a meeting with the therapy team and express their concerns in a clear and direct manner. In preparation for this meeting, the parents will write down each concern and share examples of how treatment has been inconsistent.
- c) Mary's parents should trust the therapy team. Mary's father is correct, by communicating their dislike of the program they risk offending the consultant who holds a Master's degree and many years of experience working with children with autism.
- d) Mary's parents should give up on the therapy team and entire agency. There are other agencies that will know right away what to do to best help Mary succeed. Her parents should attempt to receive services from one of these agencies.

35. Markell's father has been very depressed since his son received a diagnosis of autism. He has become withdrawn from family activities and does not like to talk about his disappointment and feelings of loss. Markell's mother has been very stressed because she is now assuming the role of organizing all of Markell's therapies and cares for Markell most of the day without very much support. *What should Markell's parents do to most directly seek support?*

a) Markell's parents could seek the support of talking to their church pastor.

- b) Markell's parents could seek a formal support group offered by their wraparound agency or another autism advocacy group.
- c) Markell's parents could seek the support of other family members.

d) All of the above.

PE Session E

36. True or False: Discrete Trial Training is adult-directed.

a) True

b) False

37. True or False: Verbal Behavior is an intervention focuses on communication development.

a) True

b) False

38. True or False: Parents should be involved in their children's treatment throughout development.

a) True

b) False

39. True or False: Medication is highly recommended for all children with ASD.

a) True **b) False**

40. PECS uses pictures for a child to communicate.

a) True b) False

Generalization

41. When Markell's mother takes him to the mall he has a tantrum if he is not able to get a pretzel from the food court. *What would you suggest that Markell's mother do to be able to shop without Markell having a tantrum in this situation?*

- a. She should plan to get him a pretzel as soon as they arrive at the mall to prevent the tantrum from occurring. It is always best to prevent tantrums with proper planning.
- b. She should try to get as much shopping completed before he starts to tantrum, and as soon as he tantrums she should rush him to get his pretzel to stop the tantrum.
- c. She should make a visual schedule that shows Markell that he can earn his pretzel after he is calm for 10 minutes in one store. After several visits where

Markell is calm and earns his pretzel, his mother can add additional stores to the schedule so he will wait longer to earn his pretzel.

d. She should try to arrange a babysitter so that she does not need to take Markell to the mall at all. Avoiding stressful situations and keeping appropriate expectations is often the best strategy for the benefit of any child.

42. Mary has stopped sitting at the table and eating dinner with her parents. When dinner is served, she will walk up to the kitchen table, pick up a piece of food with each hand and walk around her playroom while listening to her favorite songs from the TV show *The Wiggles* until she is ready for another bite. Her parents would like her to learn to sit at the table and eat her food in one place, but she tantrums every time her parents try to bring her back to the table and away from the music. *What would you suggest that Mary's parents do to have her sit and eat dinner at the kitchen table*?

- a. Since Mary really likes listening to songs from *The Wiggles*, her parents could play these songs only when she sits at the table. They could then stop playing the music when she leaves the table. Her parents will also not allow Mary to leave the table with food in order to teach her that she will only get to eat if she is at the table. Over time, Mary will begin to like sitting at the table because she gets to listen to her songs and have access to her food.
- b. Mary's parents should not allow Mary to leave the table. It is best to place her in a booster seat with a buckle and allow her to cry without providing her any attention. After a while, Mary will learn that she cannot leave the table until her parents unbuckle her from the booster seat.
- c. Mary's parents should very gradually move the kitchen table into the playroom since this is where Mary likes to eat. They could also rearrange the room so she can walk around to eat without making a mess.
- d. Mary's parents should simply ignore all of these behaviors since Mary is clearly attempting to get attention for all of these challenging behaviors. Over time, her parents' ignoring will send a clear message to Mary that she should sit at the table and eat with her parents.

43. Markell loves playing at the neighborhood playground. As often as possible, Markell's father takes him to the playground after work. When it is time to leave the playground to go home for an appointment with his least favorite therapist, Markell becomes aggressive and runs away from his father. It usually takes about 30 minutes to have Markell to leave the playground and he usually cries the entire way home. *What would you suggest Markell's father do to still spend this quality time but also have Markell leave the playground without problem behaviors*?

- a. Markell's parents could consider hiring a different therapist for Markell so he will want to leave the playground more readily.
- b. Markell's mother could begin taking him to the playground since she can usually sense when Markell will want to run away and will keep him distracted from doing so.

- c. Markell's father could have him play in their front yard so that if he begins to misbehave when it is time to go inside, they will be close to the house and Markell would not be able to run far away.
- d. Markell's parents could change the order of his activities so that his father can take him to the playground after his therapy appointment as a reward for a good session.

44. Mary really enjoys taking all of her dolls out of her toy chest and placing them in various locations in the living room. When her mother asks her to clean them up, Mary often has a tantrum and screams very loud until her mother puts away the dolls for her. While she is tantrumming, her mother often attempts to hold and rock Mary so she will calm down. However, when her father asks Mary to clean up the dolls, Mary also begins to cry and scream, but he ignores her crying and she usually stops crying within a couple of minutes and cleans up the dolls herself. *What would you suggest these parents do to have Mary clean up regardless of which parent asks her?*

- a. Mary's father could simply take over the task of asking Mary to clean up her dolls since Mary clearly responds to him more than her mother.
- b. Mary's mother could begin to ask Mary to clean up her dolls and then ignore her when she screams and cries since this is what seems to work for Mary's father.
- c. Mary's mother could show Mary a visual schedule of the steps for cleaning up the dolls and could give her a new doll every time she follows the schedule.
- d. Mary's parents could have Mary arrange the dolls in her own bedroom so it would not matter if the dolls were out of the toy chest.

45. On long car rides (lasting more than 30 minutes), Markell will unbuckle his car seat and attempt to climb up to the front seat. Each time he does this, the driver needs to pull over in order to buckle him back in his car seat to keep him safe while the car is moving. *What would you suggest Markell's parents do to teach him to keep his seatbelt on and stay in his car seat?*

- a. They could move Markell's car seat up to the front passenger seat so the driver could simply block him from unbuckling his seatbelt. After a while of blocking him in the front passenger seat, they could move him to the backseat where he will no longer try to unbuckle his seatbelt.
- b. Since Markell is clearly not happy being in his car seat, they could give Markell his favorite snacks while they are driving around to distract him from being in the car seat.
- c. Since Markell is currently able to climb out of this car seat, they could purchase a different car seat with a buckle that Markell would not be able to open. Over time, Markell will learn to stop trying to unbuckle his seatbelt on long car rides.
- d. Since Markell seems to unbuckle his seatbelt on long car rides, they could practice rewarding Markell for staying in his car seat for short periods of time (10 minutes) with special toys, snacks and praise. After a while of Markell

staying in his seat for short periods, they could gradually increase the length of time when he is in the car.

APPENDIX C

Modified Simonds & Parraga Questionnaire

PART ONE:

We would be grateful for the following general information about your child:

Name of child

Date of birth

Address.....

.....

.....

Questionnaire completed by (eg. mother, father etc.)

Date questionnaire completed

In this section we would like to know about your child's present sleeping habits. Your answers to the questions should be based on your child's sleeping habits during the LAST ONE MONTH only.

Please circle either YES or NO, tick one of the boxes or, where appropriate, write your answer

1) Does your child have a room of their own?	Yes	
	No	
2) How many other children sleep in the same room as your child?		
3) Would you normally be likely to know if your child was awake either in the evening when	Yes	
going to sleep, or in the night or in the morning?	No	
4) Does your child have a bed time routine that is followed every night? e.g. supper, bath, drink, story, kiss goodnight, light out etc.	Yes	
If YES, please describe.	No	

 5) How often does your child resist or struggle with you around bedtime? 6) How long does it take your child to fall asleep at night? 	 a) Never b) About once a month c) A few times a month d) One to two times a week e) Many times a week f) Daily a) Few minutes b) Up to half an hour c) Up to one hour d) One - two hours e) More than two hours 	
7) If your child will not go to bed or settle to sleep what do you do about it?		
8) Once asleep does he/she sleep soundly?	Yes	
9) Where does your child usually fall asleep?	 a) His/Her bedroom b) Parent's bedroom c) Sibling's bedroom d) Family /Living Room e) Other 	
 10) How often does your child wake up during the night? 11) If your child usually wakes in the night, how monotone does your shild your limit. 	 a) Never b) About once a month c) A few times a month d) One to two times a week e) Many times a week a) Daily 	
how many times does your child usually wake each night?		
12) How long does it usually take your child to fall back asleep?	 a) Few minutes b) Up to half an hour c) Up to one hour d) One - two hours e) More than two hours 	

13) What does your child do before getting back to sleep again?		
Example: crying, wandering about etc.		
14) Do you take any special steps to ensure that your child is safe if he/she wakes up during the night?	Yes	
If YES, please describe:	No	
15) Is your child a light sleeper (i.e. any noise will waken him/her)?	Yes	
	No	
16) Does your child ever sleep in unusual positions?	Yes	
If YES please describe:	No	
17) Does your child report any dreams?	Yes	
	No	
18) If he/she reports any dreams are they generally pleasant?	Yes	
	No	
19) If he/she reports any dreams are they generally unpleasant?	Yes	
	No	
20) If your child was not woken or did not have to get up in the morning, until what time would he/she sleep?		

During the LAST ONE MONTH has your child shown any of the following behaviours? Please tick the box which describes how often each behaviour happens.

Description	Never	About once a month	A few times a month	Once or twice a week	Many times a week	Daily
21. Talks in sleep						
22. Walks in sleep						
23. Grinds teeth in						
sleep						
---	-------	--------------------------	------------------------------	----------------------------	-------------------------	-------
24. Bangs head at night						
25. Has quick movements of arms or legs during sleep (eg. kicking, jump, arm flailing)						
26. Moves around a lot in bed during sleep (restless sleep)						
27. Bites tongue during sleep						
28. Snores loudly during sleep						
Description	Never	About once a month	A few times a month	Once or twice a week	Many times a week	Daily
29. Seems to repeatedly stop breathing for periods of time lasting up to 30 seconds during sleep						
repeatedly stop breathing for periods of time lasting up to 30						
repeatedly stop breathing for periods of time lasting up to 30 seconds during sleep 30. Wets bed during						

the night. He/she is not aware of their surroundings and will not remember it the next day			
33. Doesn't want to go to bed because he/she is afraid			
34. Expresses fear that if he/she goes to sleep they might die			
35. Insists on sleeping somewhere else instead of his/her bed.			
36. Afraid of the dark			
37. Needs security object (e.g. teddy bear) before he/she goes to sleep			
38. Insists on bedtime rituals (e.g. bedtime story) before sleep			
39. Needs sleeping medication			
40. During the day, muscles become so weak that he/she falls to the ground or has to lie down before falling (usually after laughing, crying or being frightened)			
41. Upon waking or going off to sleep, feels paralysed even though he/she is aware of the surroundings			
42. During the day, has urges to go to sleep and can't stop himself/herself			
43. Seems drowsy during the day, but can stop himself/herself from			

sleeping						
44. During the day, appears more active than other children						
45. Rolls from side to side rhythmically in sleep or while going off to sleep						
Description	Never	About once a month	A few times a month	Once or twice a week	Many times a week	Daily
46. Sleeps with head tipped right back						
47. Breathes through mouth rather than nose when asleep						
48. Complains of headaches on waking up						
49. Sweats a lot during sleep						
50. Reluctant to go to bed						
51. Wakes in the morning before 5 am and stays awake?						

This section asks some questions about the family's sleep and also treatments for sleep problems you might have tried.

Please circle either YES or NO and, where appropriate, write your answer

1) Have you ever had any advice or treatment for your child's sleep?

YES NO

If YES, please describe.

2) Was this advice or treatment helpful?

YES NO

3) In your opinion does your child have a sleep problem?

YES NO

If YES, what would you say this problem was?

4) Do you feel that you get enough sleep yourself?

YES NO

If NO, how does this affect you?

5) Are other members of the family affected by your child's sleep pattern?

YES NO

Please describe who and how they are affected.

6) Has anyone on either side of the family had any sleep problems (eg. nightmares, sleepwalking, night terrors, unusual jerks or movements, or other attacks)? If so, please describe and state their relationship to the child.

7) Is there anything else about your child's sleep, or anything else, that you think is important and we have not mentioned? Please give details below.

APPENDIX D

					MR	⊭: (Clir	nician u	se)	
Child's Study ID#:		Dat	e:					0.16.8.84	
DOB:	je:	1000		72007003	Sex:	a saran ka	- Children - State		
	Demogi	aphi	c Hist	ory					
What is your relationship to child?	an a	1	1.	hild (d Biolog Adopt					
Parent DOB:	Marital St 1. single 3. reman 5. marrie	ried	2. s 4. v	separa vidow livorce	ated ed				
Where were you born?	How wou your resid 1. R 2. S 3. U	lence lural luburb	(circle c		What is				
Annual Family Income (circle one): 1. Less than \$15,000 2. \$15,000 to \$30,000 3. \$30,000 to \$50,000 4. 50,000 to \$75,000 5. above \$75,000	Total nurr Jiving in y				2. 3. 4. 5.	Black Hispan Asian c Native White,		c Island an oanic	
What is the highest grade of sch completed?	ool you								
Elementary		1	2	3	4	5	6	7	8
High school Post High School (vocational tech)		1	2	3	4				
College		1	2	3	4		ree:		
Graduate/professional		1	2	3	4	Deg	ree:		
What is the highest grade of sch	ool other								
p arent completed? Elementary		1	2	3	4	5	6	7	8
High school		1	2	3	4				
Post High School (vocational tech)		1	2	3	4	Dec	ree:		
College Graduate/professional		1	2	3	4		ree:		
	Develop	men	tal His	tory					
When did your child begin to show these abilities?		Age if accomplished		Any	conce	ern?			
Sat without support:									

Demographic, Developmental and Medical Health History

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APPENDIX E

Parent Interview

- 1) Since your completion of the study, can you give me any examples of how you were able to use what was covered in the session?
- 2) Now that ____ months have passed since the completion of the study, what parts of the training you received do you feel were helpful and why?
- 3) Can you give me an example of how parts of the program were helpful?
- 4) Since the end of the study, as you think about it now, what about the program did you not find helpful? What were they and why?
- 5) Is there any other information you would like to share with me about the impact that the sessions you attended has had on your interactions with your child, or your management of your child's autism?

APPENDIX F

Instructions: Please report on all services you or your child received since the end of your participation in the BPT or PE program

Type of Intervention	Service Provider	Date Began	Date Ended	Hours per week	Group or Individual	Setting (home, school, agency office)
Counseling/Psychological Services for Child					G or I	
Counseling/Psychological Services for Parent		/ /	/ /		G or I	
Physical Therapy		/ /	/ /		G or I	
Speech and Language Therapy		//	//		G or I	
Sensory Integrative Therapy		//	//		G or I	
Recreational Sports as Intervention (e.g., swimming, gymnastics)		//	//		G or I	
Medications for Behavior Problems Name of Medication(s):		//	//	Dose:		Schedule:
Vitamin Therapy or Nutritional Supplement(s):		//	//	Dose:		Schedule:
Special Diets (e.g., grain- and dairy-free) Type of diet:		//	//			
Other, please specify:		//	//			

Have there been any significant life changes since your participation in the study? Please list:

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