Matthew's Gift: Teaching Parents of Children With Disabilities To Deal Effectively With Their Child's Problem Behavior

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MATTHEW’S GIFT: TEACHING PARENTS OF CHILDREN WITH DISABILITIES TO DEAL EFFECTIVELY WITH THEIR CHILD’S PROBLEM BEHAVIOR

by

Karolyn King-Peery

A thesis submitted to the faculty of
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In partial fulfillment of the requirements for the degree of

Master of Science

Department of Counseling Psychology and Special Education
Brigham Young University
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of a thesis submitted by

Karolyn King-Peery

This thesis has been read by each member of the following graduate committee and by majority vote has been found to be satisfactory.

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ABSTRACT

MATTHEW’S GIFT: TEACHING PARENTS OF CHILDREN WITH DISABILITIES TO DEAL EFFECTIVELY WITH THEIR CHILD’S PROBLEM BEHAVIOR

Karolyn King-Peery
Department of Counseling Psychology and Special Education
Masters of Science

This study represents a unique collaboration between the State of Utah’s Division of Services for People with Disabilities (DSPD) and Brigham Young University’s Department of Counseling Psychology and Special Education (CPSE) and the Family Studies Center. Families with children with disabilities and problem behaviors may spend 5 to 10 years on the Utah DSPD Family Support waiting list before receiving support services. Families with children with disabilities and problem behavior experience difficult challenges with limited amounts of resources. CPSE graduate students offered behavioral education to 17 families on the DSPD waiting list in the family’s homes for 10 weeks. Positive Behavior Support (PBS) provided the framework for the behavioral education. PBS takes a positive view of children with disabilities, including those with problem behavior, as they live with their families. Graduate students taught parents to use functional behavior assessment in developing a behavior support plan for their child with disabilities and problem behavior. Parents
implemented the behavior plan, and taught their child appropriate alternative behaviors. Using pre- and post-assessments, significant gains were seen in lowering the severity of the children’s inattentive, withdrawn, and uncooperative problem behaviors.
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CHAPTER I

INTRODUCTION

Matthew was a beautiful little boy. He had thick blond hair and fine features. Matthew never slept, he was always on the run, he never babbled, and he began to have problem behaviors. At 15 months, Matthew’s head stopped growing. His pediatrician began running tests to see what was causing Matthew’s language and growth delays. On the Saturday morning before Thanksgiving, my husband and I walked into the doctor’s office to wait. The doctor came in and hung up his coat and sat by us. He told us that our son had the 5p-Syndrome, or the Cri-du-chat Syndrome, a severe form of mental retardation. We got into our car and started to drive home. I kept turning and looking at Matthew to see if he had changed now that he had a clinical label, but he looked the same as he always had; he was still my beautiful little boy. In just one hour our whole world changed. Where would we go now? How would we be able to effectively deal with our son’s disability and his problematic behavior?

Statement of the Problem

Stress may be caused by the gap between what individuals perceive as the demands of society and their perceived ability to handle these demands (Janssen, Schuengel, & Stolk, 2002). Stress may also be a response to challenges such as conflict, anxiety, fear, or insecurity. Stress may manifest itself physically or psychologically (Chaney, 1996). Physically, stress may change cortisol levels, temperature, and vital signs (Janssen et al., 2002). Psychologically, stress may cause externalizing behaviors
such as aggression, or internalizing behaviors such as depression and anxiety (Johnston & Mash, 1989).

The transition into parenthood has long been recognized as a stressful event (Andresen & Telleen, 1992); parents raising children with disabilities may face physical, medical, and social challenges that typical families do not experience (Saddler, Hillman, & Benjamins, 1993). These parents may suffer high levels of stress as they cope with the added difficulties associated with their child with disabilities (Baxter, Cummins, & Polack, 1995). Typically, children with moderate to severe disabilities also have problem behaviors (Janssen et al., 2002). Family stress levels are amplified by the challenge of trying to manage the child’s disability and problem behavior and the resulting disruption of the family construct (Floyd & Gallagher, 1997). Problem behavior shades all family activities and functions and impacts the family system, family routines, and family activities (Fox et al., 2002). Feelings of stress, depression and negativity are increased by the frequent criticism from others about their perceived inability to effectively parent their child with disabilities (Herbert, 1995). Families with children with disabilities and problem behavior experience difficult challenges with limited amounts of support (Fox, Wyatte, & Dunlap, 2002).

Challenging or problem behaviors may be divided into two categories—external and internal. External behaviors disrupt the environment such as aggression toward others, over activity, and temper tantrums; or behaviors that disrupt the individual such as head banging, hand flapping, and rocking. Internal behaviors include depression and anxiety (Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002; Elgie & Hastings,
Without intervention, challenging behaviors do not improve with age and most often become worse (Koegel, Koegel, & Dunlap, 1996).

Mothers are the primary caregivers of children with disabilities and problem behaviors and may experience feelings of exhaustion, emotional instability, and stress as they search for ways to cope (Floyd & Zmich, 1991; Fox et al., 2002). Mothers may feel higher levels of stress than fathers because of the unending, extensive demands associated with the daily care of the child with disabilities (Gavidia-Payne & Stoneman, 1997). Mothers are more prone to feelings of depression and despair, often questioning their competency, especially if their child also has difficult behaviors (Saddler et al., 1993). Stress may also affect the reciprocal, interactive behaviors between parent and child, and the quality of the parent-child relationship (Andresen & Telleen, 1992).

Single mothers experience even greater child-related stress as a result of limited support from within the home (Floyd & Gallagher, 1997). In addition, mothers with higher educational and socioeconomic levels are usually more adept at coping with stress productively, and their children with disabilities are given a better prognosis for improvement of behavior (Saddler et al., 1993).

Individuals with disabilities also experience stress. The level of stress individuals with disabilities feel is determined by the level of their intellectual disability, their ability to process and appraise information, their need for structure, and their limited repertoire of appropriate behaviors (Cheney, 1996). Challenging or problem behaviors may be the result of the maladaptive ability of individuals with moderate to severe disabilities to handle even low levels of stress (Janssen et al., 2002).
Chronic stress may increase problem behaviors such as self-destructive behavior, aggression, depression and anxiety (Cheney, 1996).

Feelings of stress may lead parents raising children with disabilities and problem behavior to seek family support. Family support refers to “any and all actions that serve to strengthen and sustain the family system, especially as these actions pertain to the family’s assimilation and understanding of the child’s disability” (Koegel et al., 1996, p. 41).

Statement of the Purpose

Family support has been funded since the early 1980s in the United States. In Utah, the Division of Services for People with Disabilities (DSPD) under State Human Services provides family support services. Money for family support services is allocated to families with children with disabilities according to the family’s level of crisis on a weighted scale. Families who receive family support are provided with ongoing funds to help the family to continue the home placement for their child with disabilities. Presently there is a 5- to 10-year waiting list for families in Utah to receive these support services. Currently, 165 families are on the Utah County waiting list. DSPD workers suspect that while families wait for services, many parents divorce, go bankrupt, or place their child in state institutions (D. Maughn, personal communication, September 30, 2002).

While families are waiting for family support state assistance, they may participate in the Utah Family Council. The Utah Family Council is an organization developed to provide family-to-family support. The council was initially developed by
DSPD to help families provide a parent-to-parent support system, and is now an independent group. The council meets monthly throughout the state. The monthly meetings address issues faced by families raising children with disabilities. Participation in the council is voluntary.

The purpose of this research project was to provide parent behavioral education training for families currently on the DSPD Family Support waiting list. This research project was an effort to reduce family stress, decrease problem behavior, increase appropriate child behavior, and improve parent-child relationships.

Theoretical Framework

The Resiliency Model of Family Stress, Adjustment, and Adaptation provided the theoretical framework for this research. This model, used by Brigham Young University (BYU) researchers Mandleco, Olsen, Dyches, and Marshall (2003) in their work with family adaptation to disability, represents the relationships among problem solving and coping, and resources and social support in the adaptation and adjustment to family stress over time (McCubbin & McCubbin, 1989; McCubbin, McCubbin, & Thompson, 1993).

With the birth of a child with disabilities, the family’s current patterns of functioning may no longer be adequate for the new situation. The family must change in areas of family schema, sense of coherence, paradigms, and situational appraisal. The family must look for new resources and supports that will provide them with the new capabilities that they now need. Family routines may be altered, family roles may be re-examined, and new patterns, roles, and expectations developed. New paradigms may
emerge to reinforce and legitimate the new way the family is functioning. Without this, the family will have lower amounts of stability (McCubbin, Thompson, & McCubbin, 1996).

BYU faculty from Counseling Psychology and Special Education (CPSE), Marriage, Family, Human Development, and Nursing (MFHD) created an interdisciplinary team to study how families adapt to raising a child with a disability. Marilyn McCubbin, an internationally distinguished expert in family adaptation, was invited as a consultant from the University of Wisconsin/Madison School of Nursing, to provide theoretical and empirical foundations for the research undertakings. After considerable planning, sharing literature, and goal setting, this research group has collected data on multiple variables related to family adaptation. The Family Studies Center project, of which this masters research is a piece, continues to fill the important need to collect ongoing data on children with severe disabilities, their behavioral problems, their family’s adaptation to the their child’s behavior difficulties, and the incidence of family stressors (Wilder et al., 2002).

Fortunately, every difficult behavior does not need to be eliminated in order to improve family stress levels (Sofronoff & Fabotko, 2002). Applied Behavior Analysis, a scientific technology, has been utilized effectively to decrease problem behavior.

Applied Behavior Analysis

Applied Behavior Analysis (ABA) was developed from the work done in experimental analysis of behavior in lower organisms’ behaviors (Skinner, 1974a, 1974b). Skinner was the first researcher in behavior analysis to distinguish the operant
conditioners of behavior that are concerned mostly with consequences of the behavior and the relationship between behavior and the consequences that come from the behavior (Alberto & Troutman, 1999). Skinner (1974a, 1974b) recognized that behaviorism was the scientific analysis of intentions, motivations, and its goals and purposes. Behavior had a function, and looking at that function makes the study an “elegant and pragmatic philosophy of human behavior” (Repp & Horner, 1999, p. 10).

Through the use of ABA, important contributions were made in working with individuals with mental disabilities, resulting in the ability to change problem behavior. Using elements of ABA, target behaviors are identified, intervention is implemented, and data are collected showing the effectiveness of the behavior intervention (Bailey & Burch, 2002). When working with parents to change their children’s problem behavior, the most effective and ethical treatments need to be followed, by looking at similar programs that have been proven to be effective with a similar behavior with similar children (Alberto & Troutman, 1999).

Only recently have practitioners moved from the traditional expert-driven ABA model to a more collaborative parent-professional model called Positive Behavior Support (PBS; Carr, 1997; Dunlap, Newton, Fox, Benito, & Vaughn, 2001; Hienemen & Dunlap, 1999). PBS is proclaimed as the “new applied science” of behavior change with comprehensive interventions that are applied in natural contexts of home and family that focuses on broader lifestyle results (Carr et al., 2002; Fox et al., 2002).

PBS represents an evolution of applied behavior analysis toward a new applied science that views consumers of research as collaborative partners, values ecological
and social validity, as well as internal validity, seeks to promote lifestyle changes, and views social systems as units of analysis and intervention (Carr, 1997; Carr et al., 2002; Lucyshyn, Dunlap, & Albin, 2002; Turnbull, Friesen, & Raminez, 1998).

PBS is characterized by principles that include independence, productivity and inclusion that offer a holistic, multifaceted approach to providing individualized supports and services (Turnbull & Ruef, 1997). PBS expands the unit of analysis and intervention to focus on family routines rather than isolated behaviors (Lucyshyn, Blumber, & Kayser, 2000). PBS includes using functional behavior assessment, changing events that trigger problem behavior, teaching communication skills, increasing the child’s range of interests, minimizing punishers, choosing procedures that are least intrusive as possible, and maintaining the child’s dignity (Horner et al., 1990a, 1990b).

The purpose of this study was to help families raising children with disabilities and problem behaviors. This was accomplished by providing parents with behavioral education using PBS, including the use of functional behavior assessment to develop and implement a behavior support plan for their child with disabilities and problem behavior. We investigated whether the behavioral education improved outcomes for these families, and lowered levels of family stress, as their child’s behavior improved. To determine the outcome, parents completed pre- and posttests.

Research Questions

The following questions guided this study.

1. What are the differences in pre and post ratings of problem (maladaptive)
behavior and the behavior’s frequency and severity on the Scales of Behavior-Revised (SIB-R) as rated by mothers?

2. What are the differences in pre and post ratings on the Limit Setting subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?

3. What are the differences in pre and post ratings in parental support on the Support Subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?

Personnel from the DSPD acknowledge that we may find that behavioral problems in children with disabilities constitute one of the greatest sources of stress in families seeking DSPD Family Support as indicated in the initial DSPD intake interviews. We contend that by providing parents with behavioral education using PBS to effectively deal with their children’s problem behavior we will reduce the levels of stress these families experience.
CHAPTER II
REVIEW OF LITERATURE

“Families are the most committed, enduring, and knowledgeable source of personal support available for their children” (Dunlap et al., 2001, p. 215). Families are experts in knowing their child, the child’s history, behavioral tendencies, what they prefer, and what their special abilities are. No two families are the same; families are highly individual and diverse systems (Dunlap & Fox, 1996, Koegel et al., 1996). It is important for professionals to address the family’s needs on an individual basis and to be cautious of stereotypes (Ainge, Colvin, & Baker, 1998). Ainge and colleagues suggested that in an effort to avoid stereotyping, professionals use parent interviews and formal and informal surveys to help them assess parent responses to critical issues in parenting a child with intellectual disabilities before services are planned. By doing this, professionals could be more sensitive to the needs of the family and child, and may deliver more appropriate services.

The Need for Family Support

Researchers indicate the need for family support. Turnbull and Ruef (1997) interviewed 17 families in an effort to determine inclusive lifestyle issues that were important to these families and their children with disabilities and problem behavior. Two pervasive themes were noted, first, that a majority of families expressed their feelings of exhaustion and frustration as they were the primary individuals to instigate and choreograph their child’s opportunities for an inclusive lifestyle, and second, that families felt they needed more support.
Fox et al. (2002) completed a qualitative study of 20 families with children ages 3 to 12 years. As part of this study, parents received family support by participating in six group meetings every other week. In-home family support was provided between meetings. During the home visits, parents were interviewed at the beginning and ending of the behavioral program. Three themes emerged from the interviews, “Something is not right,” “A shoulder to cry on,” and the most pervasive theme of “it’s a 24-hour, 7-day involvement.” Parents went through emotional stages in learning that their child had disabilities; they identified their need for family support and that their child with disabilities needed incessant care.

In a meta-analysis of 66 studies, Andresen and Telleen (1992) evaluated the relationship between family support and maternal behaviors and attitudes. Informational support enabled the parents to problem solve. They noted that it was also essential that professionals working with mothers assess the availability of emotional support. This is critical because stress and a lack of family support affected the mother’s response to the child’s physical and emotional needs, the verbal interactions with her child, and infant stimulation or play interactions—which in turn affected the child’s responsiveness, temperament of quieting, and adaptability to parent cues, compliance, attachment, and behavior problems.

In the past, Quine (1986) found that children with behavior problems necessitated that mothers do more work housekeeping, and larger amounts of laundry, and that their children required more help with dressing, washing, and toileting because they were unable to do so on their own. Nonemployed, nonpartnered mothers
experienced even greater levels of stress and depression. Single mothers with low
family income felt unrelieved in their daily responsibilities of caring for their child.

In general, single mothers of children with disabilities, appear to be at risk for
depression and reduced psychological well-being. This risk appears especially
ture for those unmarried mothers who are truly single (without a supportive
intimate partner) and who are either not employed or are working essentially
full-time, with little or no outside source of income. (Gottlieb, 1997, p. 11)

More recently, Gavidia-Payne and Stoneman (1997) reported that mothers who
received family support experienced less stress, were able to consistently employ a
variety of coping strategies, and tended to become more positively involved in their
child’s care. Mothers who had a supportive male partner experienced less depression. In
addition, mothers who were employed but had other important income sources
experienced less stress, depression, and fewer health problems than those who were not
employed (Gottlieb, 1997). Gavidia-Payne and Stoneman also found that fathers are
faced with different stressors and may use different resources and coping orientations.
When fathers rated their family environment as more harmonious, cohesive, and orderly
they experienced less stress and felt more support.

Positive Behavior Support

One strategy that may increase support and reduce stress within families with
children with disabilities with behavior problems is Positive Behavior Support (PBS).
PBS takes a positive view of children with disabilities, including those with problem
behavior, as they live with their families (Lucyshyn et al., 2002). PBS emphasizes
child-centered goals that reduce problem behavior within the family context, that
support child health and safety, that improve communication and daily living skills for
the child, that offer participation of meaningful daily and weekly routines and activities with family members and peers, and that confer parent empowerment as they are able to implement behavior supports that increase the quality of daily family activities at home and in the community, and continue to solve behaviors using PBS principles (Fox, Dunlap, & Philbrick, 1997; Lucyshyn & Albin, 1993; Lucyshyn et al., 2002). With families, PBS takes into consideration family perspectives and family systems when defining meaningful and durable outcomes, and when designing behavior support plans (Lucyshyn et al.). PBS is an intervention approach that is both child and family-centered.

The purpose of this science is to develop a technology of behavioral support that is effective, acceptable, and feasible when used in typical homes, schools, and communities by families, professionals, and other care or service providers (Carr, 1997; Lucyshyn et al., 2002). PBS integrates values that are person-centered, practices that are evidence-based and scientific methodology (Carr; Fox et al., 2002; Horner et al., 1990a, 1990b; Koegel et al., 1996). PBS is collaborative and assessment-based in developing effective, individualized interventions for people with disabilities and problem behavior. PBS intervention plans emphasize the use of proactive, educative, and reinforcement based strategies to achieve meaningful and durable behavior and lifestyle outcomes (Dunlap et al., 2001; Lucyshyn et al.). PBS supports should allow the individual durable, generalizable behavior changes that provide increased access to community settings, social contacts and preferred events (Horner et al., 1990a, 1990b; Turnbull & Ruef, 1997).
The PBS approach encourages parent education and family support, to empower families as they implement behavior support strategies with fidelity, to promote durable improvements in behavior and in child and family lifestyle, and to solve new or reoccurring behavior problems with little or no professional assistance (Lucyshyn et al., 2002). The most helpful professionals are those who provide emotional support and encouragement (Fox et al., 2002). Emotional support raises the parent’s self-esteem and provides the confidence need to carry out the parental role (Andresen & Telleen, 1992). Sporonoff and Farbotiko (2002) defined self-efficacy as how emotionally confident parents feel in their ability to handle their child’s behavior problems. They further noted that low levels of parental self-efficacy often resulted in poor persistency, depression, and diminished satisfaction in the parenting role.

**Positive Behavior Support Principles**

Three basic PBS principles emerge in the literature. The three principles include collaborative approaches, the use of family systems theory, and a foundation in applied behavior analysis (ABA).

*Collaboration*

The first step in designing a PBS intervention that will facilitate mutual problem solving is the development of a relationship between the professional and the family, so that the professional can more fully understand the family’s structure, its capabilities, important routines, and needs (Marshall & Mirenda, 2002). Relief, joy, and synergy occur when professionals collaborate with families as valued colleagues and decision-making partners (Lucyshyn et al., 2000). Families value professionals who recognize
the family as having expertise to share regarding their child, and who conduct assessment and intervention activities in the home (Lucyshyn et al.). Families appreciate professionals with technical competence who demonstrate sincerity, humility, and an enduring interest in empowering family members (Lucyshyn et al.). Professionals and families, working as a partnership, develop a vision of what the child’s inclusion in both family and community life may look like. Together, they may also develop a plan that has a good fit with cultural and ecological family features (Lucyshyn et al.)

The parent-professional collaborative process may improve the willingness of the family to continue ongoing implementation of the behavior plan after the initial stages are completed and supports are discontinued. This happens because the intervention has become integrated into the family’s lifestyle (Albin, Lucyshyn, Horner, & Flannery, 1996; Marshall & Mirinda, 2002).

*Family Systems*

The well-being of the family system may be a leading factor in the child’s ability to mature and progress (Dunlap & Fox, 1996; Koegel et al., 1996; Robbins, Dunlap, & Plienis, 1991). The family system becomes engaged in multiple accommodations in an effort to survive under the pervasive effects of the child’s disability and problem behavior (Fox et al., 2002). The family schema or family’s appraisal process changes with the birth of their child with disabilities.

Families are highly diverse systems with different levels of motivation, understanding, desire to participate, and cultural beliefs and practices. Families should
be encouraged to be involved to the fullest level that they can manage to function given their diverse circumstances and priorities (Dunlap et al., 2001).

When trying to solve family problems and managing family life when a child has a disability, the family’s culture fundamentally influences two critical levels of family appraisal involved in the process of adaptation: the family’s schema and paradigms. These processes, of family life, are the ways in which families give meaning to having a child with disabilities, and they appear to play a fundamental role in shaping the family’s responses and strategies in the initial and follow-up medical care and treatment. Family schema is defined as the “structure of fundamental convictions and values shaped and adopted by the family system over time, which creates the family’s unique character and serves as an overriding shared informational framework against and through which family experiences are processed and evaluated” (McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993, p. 1064).

Deatrick, Knafl, and Murphy-Moore (1999) defined the attributes for family normalization as those that (a) define family life as essentially normal, (b) acknowledge existence of the impairment (and potential threat to lifestyle), (c) define the social consequences of the situation as minimal, and (d) engage in behaviors designed to demonstrate the essential normalcy of the family to others. For family normalization to happen, professionals need to develop a treatment regimen that is consistent with normalcy, which engages in positive parent behaviors, and builds family routines that are consistent with normalization.

For many families, applied behavioral science and family-centered values may
not be sufficient conditions for promoting meaningful and durable behavior and lifestyle changes for a child with a disability, because knowledge about the family system or ecology may be necessary as well (Egel & Powers, 1989; Lucyshyn et al., 2002). PBS is influenced by ecological family theories such as the Family Stress and Adaptation Theory (McCubbin & Patterson, 1983; Singer & Irvin, 1991). This family theory includes focusing on interventions that improve family structure, functioning, and relationships; positive coping strategies that focus on child strengths and feelings of gratitude; and activity settings that are family centered, culturally sensitive and sustainable (Lucyshyn et al.).

Family resiliency is strengthened by family coping strategies that help the family develop an optimistic outlook and acceptance of their new family construct. Coping strategies may involve direct action to eliminate and reduce the intensity of the demands (this may include outside the home placement). Other coping strategies may include acquiring more resources that have not been used by the family in the past. Also, involvement in managing stress by participating in activities that facilitate enjoying the companionship of other family members, applying appropriate humor, expressing feelings in non-blaming ways. Furthermore, coping strategies may involve family appraisal that makes the way the situation is seen as more constructive, manageable, and acceptable by all members of the family. Families reframe the situation by placing the family’s experience into a broader value set. A family may then feel less threatened over time when the situation is viewed as a spiritual challenge, and part of the natural ebb and flow of nature, gradually affirming the adoption of a new
pattern of family functioning (McCubbin et al., 1996).

*Functional Behavioral Analysis*

“People do not engage in self-injury, aggression, severe property destruction, or seriously disruptive behaviors solely because they have mental retardation or other developmental disabilities…they engage in patterns of behavior that have worked for them and continue to work for them in some way” (O’Neill et al., 1997, p. 8).

Additionally, young children do not outgrow problem behavior (McNeil, Capage, Bahl, & Blanc, 1999). Problem behavior may serve four broad functions, communication, acknowledgement, stimulate sensory needs, or to provide escape. Moreover, problem behavior may be associated with poor communication skills attributed to speech challenges that are often part of the child’s type of disability (Koegel et al., 1996; Quine, 1986). It may evoke the need the child may have for attention, nurturing and comfort from others (Carr & Newsom, 1985; Carr, Newsom & Binkoff, 1980; Repp & Horner, 1999). Problem behavior may be an effort to access desired items or activities (Derby et al., 1992; Durand & Crimmins, 1988; Repp & Horner). It may be used to generate sensory stimulation that can be visual, auditory, or tactile (Favell, McGimsey, & Schell, 1982; Repp & Horner, 1999; Rincover, Cook, Peoples, & Packard, 1979; Rincover & Deveny, 1982).

Behavior can be predicted and changed by understanding the function, predictors, and consequences of the problem behavior. Functional assessment is a tool that may be used to change the focus from treating the child from within, to designing effective environmental routines (Crone & Horner, 2003). To increase appropriate
behavior and decrease problem behavior, it often requires the use of comprehensive changes in the child’s routines that are problematic, increasing the student’s repertoire of skills, and improving the child’s interactions with adults (Crone & Horner). PBS is helpful in designing behavior support around the family’s routines at home and in the community that are not presently working because of the child’s problem behavior. “By focusing on valued but unsuccessful routines, interventions not only improve child behavior, but also address family goals and visions for the future” (Lucyshyn et al., 2000, p. 25).

A holistic team effort, that includes parents, siblings, teachers, and professionals, is necessary to cover all aspects of the child’s lifestyle. Team effort is critical for long-lasting behavior improvement. Individuals make greater progress if they are provided with choices (Brown, 1996). Empowerment in their environment directly relates to having children be consulted about their wishes and choices. When routines have opportunities for children to use choice, task initiations increase, and problem behaviors such as aggression decrease. “Choice making is a right. Multiple, individualized opportunities are needed if choice making is to be meaningful to persons with severe disabilities” (Bambara, Koger, Katzer, & Davenport, 1995, p. 194).

Clinical Use of Applied Behavior Analysis

“Without a doubt, functional analysis constitutes the most powerful tool for identifying the purpose of problem behavior” (Repp & Horner, 1999, p. 21). In the past, Functional Behavior Analysis (FBA) has been applied in an outpatient or clinical setting for individuals with disabilities and problem behaviors. Trained professional behavior
analysts spent hours completing the FBA procedure. Functional analysis procedures were completed and documented while the behavior analysts delivered the consequences for the child’s behavior (Crone & Horner, 2003). Family involvement in FBA was primarily restricted to identifying the problem behavior, identifying antecedents, and in developing a hypothesis (Repp & Horner). Harding and colleagues (1999) clinically studied the effect of parents providing their children with choices, in an effort to determine effective consequences as part of the FBA hypothesis. Their investigation showed that positive reinforcement associated with access to parent attention, specific toys, or both, could influence appropriate behavior. However in the past, few families have participated in the FBA hypothesis-testing process (Peterson, Derby, Berg, & Horner, 2002).

Functional Analysis (FA)

The purpose of a FA is to develop an understanding of the relationship between the child’s problem behavior and the events in the environment (Dunlap et al., 2001). Functional behavior assessment involves identifying the problem behavior, collaborating in an effort to devise a hypothesis of the function of the behavior, and identifying the context of the family routines for the intervention (Marshall & Mirenda, 2002). Carr (1997) was the first researcher in ABA to argue that there needed to be a system whereby behavior interventionists could develop a hypothesis for the conditions that maintain the child’s problem behavior and from this hypothesis develop the behavior plan (Repp & Horner, 1999). Functional assessment should provide information about the behavior, the structural features of the environment, and the
behavior patterns of the people that provide support for the individual (O’Neill et al., 1997). The essential reason for completing a functional assessment is to develop an effective behavior plan (Dunlap et al.). “The purpose of functional assessment is to increase the effectiveness and efficiency of behavior support plans (O’Neill et al., p. 65).

FA must be a prerequisite step to developing PBS, and families represent the greatest resource for the intellectual and emotional development of their children (Dunlap et al., 2001). Many parents are able to identify why their child engages in problem behavior; however, they often do not know how to respond to the behavior, or how to effectively discipline their child (Fox et al., 2002). Families that have insights about the problem behavior are frequently aware of what antecedents, or triggers, result in problem behavior, and have already used preventative measures and made adaptations in their daily family routines to prevent future problems (Dunlap et al.).

Three ways to identify the functions of problem behavior include functional analysis, direct observation, and the use of interviews (Repp & Horner, 1999). Developing an FA by parent reports and observations needs to include enough data to see clear patterns of the behavior (Dunlap et al., 2001). A summary statement may be effectively used to describes the situation, the behavior, and the function of the behavior or reinforcement outcomes, “When [antecedent] occurs, [person] [behavior] in order to [consequence] [function]” (O’Neill et al., 1997).

Behavior Support Plans

Behavior Support Plans are developed utilizing information from the functional
behavior assessment (FBA). Involving families in the FBA and the development of the Behavior Support Plan benefits the family and increases the validity and efficacy of the plan (Dunlap et al., 2001). Families are not only vital contributors in the behavioral assessment, but also in the implementation and application of the behavior plan (Dunlap et al.). Participating in the process of developing a behavior plan from the FBA, families are able to directly observe how their behavior contributes to their children’s appropriate and inappropriate behavior (Harding, Wacker, Berg, Barretto, & Rankin, 2002).

There are four principles to consider when developing behavior support plans. First, the plan should include how the family and other support individuals will make changes as well as the individual the plan is being developed for. Second, the plan should be based on the information gathered from functional assessment. Third, the plan should be consistent with laws of human behavior and be technically sound. Fourth, the plan should fit well with the participant’s values, resources, and skills of those implementing the behavior plan (O’Neill et al., 1997).

Developing a behavior support plan must be sustainable within the available resources and environment, conditions and systems, and it must be suitable for the specific needs of the individual with the problem behavior. The implementation of a behavior support plan increases if all involved persons are comfortable with the plan, goals, and strategies, as well as, feel that the plan will be successful (Albin et al., 1996; Koegel et al., 1996).

Active involvement of families in the design and implementation of the behavior
intervention and the scope of changes that may be required may be the most important variable in determining its effectiveness, fidelity, and durability (Marshall & Mirenda, 2002; Vaughn, Dunlap, Fox, Clarke & Bucy, 1997). Effectiveness of the intervention depends on how well procedures fit ecological and family contexts of the family implementing the plan (Marshall & Mirenda; Snell, 1997). Behavior support plans should be designed to support families throughout their daily routines and functions of family life (Lucyshyn et al., 2000). In the past, traditional interventions failed because the family did not feel the plan was a “good fit,” causing precious time and energy to be wasted (Marshall & Mirenda). After implementing the behavior support plan, affects of the plan are systematically evaluated to guide adjustments and refinements to the plan (Peterson et al., 2002).

Conclusion

PBS is an effective tool for working with families who have children with disabilities and problem behaviors. PBS principles of collaborating, employing the use of family systems theory, and implementing applied behavior analysis technology, can effectively decrease problem behaviors and improve the lifestyles for families and their children with disabilities and problem behaviors.
CHAPTER III

METHODS

Design

One group pre-and posttest design was used for this study. Paired t tests were used to compare pre and post PCRI and SIB-R ratings. Additionally, qualitative data was gathered from parents pre and post during the initial interview with the parents by the BYU graduate student. The study is limited by the DSPD International Review Board’s denial to approve the use of a control group.

The independent variable in this study was the behavioral education. CPSE graduate students and parents worked together to complete the parent handbook, which provided the framework for the behavioral education. The dependent variable was the gain of ratings between the pre to post SIB-R Problem Behavior and the pre to post PCRI Limited Setting and Parental Support subscales.

Participants

Parent Participants

Parent participants included in this study are currently on the waiting list for the DSPD Family Support in Utah County. Utah DSPD Family Support provides financial, medical, and/or emotional support through participation in the Family Council, and respite services. Families were recruited from this program because they have already identified their need and desire for support. Many of these families are at high family crisis levels.

The families seeking DSPD Family Support have previously met with a DSPD
intake worker in their homes. During this meeting, the family was interviewed and given the Inventory for Client and Agency Planning (ICAP) assessment and DD/MR or Brain Injury Needs Assessment and Intake forms. After completing the interview, family needs were assessed and weighted according to DSPD formulas. Families were then placed on the waiting list in rank order according to their intake scores. Families with the highest scores, indicating the greatest need, receive services first. However, it is possible and likely to be near the top of the list and still wait several years to receive services.

Alan Tribble, State DSPD Behavior Analyst, and Tiffani Ortega, DSPD Intake Worker, determined the families that were selected for this study. Researchers were not aware of the number of families that received the letter introducing the study (Appendix A) and the Consent for Participation form (Appendix B). Mr. Tribble selected nineteen families from the forms that were returned. He also asked us to write letters of non-selection to four families. From the initial nineteen families, two did not meet age requirements and one declined to participate because the child’s behavior was no longer a problem. Seventeen families received the behavioral education. Sixteen of the families were white Caucasian, and one family was Hispanic. All materials were translated into Spanish for the Hispanic family by their assigned graduate student.

Twelve boys and five girls participated in the study. Their ages included: 1 child at 3.8 years, 1 child at 4 years, 1 child at 6 years, 4 children at 7 years, 3 children at 8 years, 1 child at 9 years, 4 children at 10 years, 1 child at 11 years, and 1 child at 14 years. The disability categories for the children were as follows: 5 children with
intellectual disabilities including Down Syndrome, Cri-du-Chat Syndrome, and Turner Syndrome; 1 child with Developmental Delay and Acquired Traumatic Brain Injury; 6 children with Autism; 1 child with an Utero stroke and Attention Deficit Disorder; and 2 children with Cerebral Palsy (one of which also had Autism).

**CPSE Graduate Students**

Participants in this study also included BYU graduate students in the Department of Counseling Psychology and Special Education (CPSE). Graduate students in the School Psychology program were concurrently taking a functional behavior analysis course, while graduate students in Special Education had prior course work in functional behavior analysis. For this study, graduate students were enrolled in the CPSE 610 Collaboration/Consultation within School and Family Systems course. As part of the course work, graduate students worked with families with children with disabilities and problem behavior that had been identified for this study. All graduate students were fingerprinted and had background checks similar to what is required for teachers in the State of Utah.

Graduate students were informed about privacy and confidentiality rights of the participants. During course instruction, graduate students were taught awareness of Utah’s mandatory reporting laws (if they observed or suspected abuse, neglect, or exploitation), following State law requiring them to report to Adult Protective Services (APS), Child Protective Services (CPS), or the nearest law enforcement agency (being a misdemeanor offense if not reported). Graduate students reviewed and signed a confidentiality agreement when they were given their assigned families (Appendix G).
Settings

One graduate student met weekly with his/her assigned parents participating in this study in the families’ homes. Family homes are the natural environment to work with parents. In the past, parents have received parent training from licensed professionals including psychologists, therapists, and social workers and in clinics or school settings (Dembo, Sweitzer, & Lauritzen, 1985; Grazian & Diament, 1992; Rotto & Kratochwill, 1994). For this study, having graduate students provide behavioral education in the family homes potentially offers positive advantages for the parents and for the child with disabilities and problem behavior. Within the home setting, parents can more easily and consistently collect data (Wierson & Forehand, 1994). Also, using the home setting diminishes the need for generalization training and behavior maintenance from clinic to home (Fox et al., 2002; Marchant & Young, 2001).

As parents were trained in behavioral education, children could be in the same room playing, sitting with the parent or in and out of other rooms in the house. The graduate student did not work alone with the child in the room. Furthermore, the graduate student did not work with one parent of the opposite sex alone in the home setting (not including the child with disabilities).

The option of working at BYU McKay Building room 350 (a suite of rooms) was also available for parents who felt uncomfortable having graduate students meet with them in their homes. Each room in the clinic had three to four chairs and a small table. No family in this study chose the McKay School room option.
Instrumentation

Three instruments were used for this study. Parents completed a Parent-Child Relationship Inventory (PCRI), a Scales of Independent Behavior-Revised (SIB-R), and a confidential parent survey (see Appendix E) with their graduate student at the beginning and at the end of the study. Parents and graduate students used the parent handbook to guide instruction in the behavioral education (see Appendix H).

*Parent-Child Relationship Inventory (PCRI)*

The PCRI was developed to assess parent attitudes toward their children and their parenting skills. The PCRI looks specifically at aspects of the parent-child relationship that may be problematic, as well as providing an overall picture of the quality of that relationship (Gerard, 1994). “The PCRI helps to put qualitative impressions in perspective by making normative comparisons possible (Gerard, 1994, p. 1). The PCRI uses items that were rated by expert judges, eliciting professionals and test takers to provide qualitative feedback, and collecting additional empirical data and item analysis (Gerard, 1994). The PCRI was given to 1,100 parents in the United States (divided into four regions, Northeast, South, Midwest, and West) for standardization. Data was collected using schools and daycare centers.

The PCRI is divided into eight sections: Support, Satisfaction with Parenting, Involvement, Communication, Limit Setting, Autonomy, Role Orientation, and Social Desirability. A 4-point Likert scale is provided for responses including: Strongly Agree, Agree, Disagree, and Strongly Disagree. Limit Setting and Parental Support scales were chosen for their relevance to this study.
Limit setting. The Limit Setting subscale measures effective discipline strategies. “Discipline typically fails when it does not establish limits” (Gerard, 1994, p. 10) for the child. Discipline may reflect the style and effectiveness of parenting (Gerard). “Very Low Limit Setting scores (below 30T) Suggest a situation in the home that is out of control: The parent may feel besieged and angry, and the child may perceive attempts at discipline as inconsistent or hostile” (Gerard, 1994, p. 10). PCRI Limit Setting includes 12 statements. These questions included:

1. I have trouble disciplining my child.

2. I have a hard time getting through to my child.

3. My child is more difficult to care for than most children are.

4. I sometimes give in to my child to avoid a tantrum.

5. I wish I could set firmer limits with my child.

6. My child is out of control much of the time.

7. I wish my child would not interrupt when I’m talking to someone else.

8. I often lose my temper with my child.

9. My child really knows how to make me angry.

10. I sometimes find it hard to say no to my child.

11. I often threaten to punish my child but never do.

12. Some people would say that my child is a bit spoiled (p.38).

Each statement had a 4-point Likert scale that consisted of: “1” Strongly Agree, “2” Agree, “3” Disagree, and “4” Strongly Disagree.

Parental support. The Parental Support subscale measures the emotional and
practical support parents may feel. High ratings indicate that parents feel like they are getting the support they need, which allows them to provide better childcare. Low ratings indicate that parents may feel less supported and are seriously overburdened.

PCRI Parental Support included nine statements.

1. When it comes to raising my child, I feel alone most of the time. (-)
2. I worry a lot about money. (-)
3. I sometimes wonder if I am making the right decisions about how I raise my child. (-)
4. I get a great deal of enjoyment from all aspects of my life. (+)
5. I sometimes feel if I don’t have more time away from my child I’ll go crazy. (-)
6. My life is very stressful right now. (-)
7. I sometimes feel overburdened by my responsibilities as a parent. (-)
8. I’m generally satisfied with the way my life is going right now. (+)
9. My spouse and I work as a team in doing chores around the house (+)

Each question had a 4-point Likert scale that consisted of “1” Strongly Agree, “2” Agree, “3” Disagree, and “4” Strongly Disagree.

The PCRI has two validity indicators embedded within the measure. The Social Desirability indicator points to the parent’s need to give answers that are socially acceptable instead of what they may actually be feeling. The Inconsistency indicator measures the parent’s propensity towards responding inconsistently.
Problem behaviors are those behaviors that are socially unpleasant to others, that interfere with a person’s ability to cope within their environment, and that are repetitious or very unusual in a typical social context (Morreau, 1985). Problem behavior has been recognized as one of the largest barriers to school, work, and community involvement. Problem behavior may also be one of the chief causes for individuals with disabilities to be placed in more restrictive environments outside the home (Bruininks, Olson, Larson, & Lakin, 1994). The Problem Behavior Scale was developed using Morreau’s 170 identified discrete problem behavior distinguished by 1,500 teachers and caregivers working with children with and without disabilities. This list of behavior was further validated independently using 2,000 randomly sampled residents with mental disabilities in public and private residential facilities.

The SIB-R assesses two general areas of adaptive behavior and maladaptive behavior. This study uses the maladaptive behavior section to look specifically at problem behavior. The items on each of the maladaptive behavior subscales advance from easiest to most difficult developmentally, allowing assessment for individuals from birth to eighty years old, and may be used with individuals with mild to profound disabilities. In the past, measuring maladaptive behavior was generally done by using a list of maladaptive behavior and then counting how many of the behaviors the individual demonstrated. This list could not be long enough to give all of the possible problem behaviors. If the list did not include a problem behavior the individual had exhibited, then the score would be too low. Not all problem behaviors are equally
important. In addition, the frequency of the behavior was not addressed, and frequency and severity interactions were not considered (Bruininks, Woodcock, Weatherman, & Hill, 1996).

The maladaptive behavior subscale is given without a basal or ceiling and only looks at present behavior problems. Maladaptive behavior includes the following items: Hurtful to Self, Hurtful to Others, Destructive to Property, Disruptive Behavior, Unusual or Repetitive Habits, Socially Offensive Behavior, Withdrawal or Inattentive Behavior, and Uncooperative Behavior. After the most problematic behavior in each category is identified, frequency is recorded using a 5-point Likert scale: Less than once a month, One to 3 times a month, One to 6 times a week, One to 10 time a day, and One or more times an hour. Intensity, or the severity of the problem behavior, is recorded on a 4-point Likert scale: Not Serious; Not a Problem, Slightly Serious; a Mild Problem, Moderately Serious; a Moderate Problem, Very Serious; a Severe Problem, Extremely Serious; a Critical Problem.

The eight problem behavior categories are then organized into four maladaptive indexes: Internalized Maladaptive Index (IMI), Asocial Maladaptive Index (AMI), Externalized Maladaptive Index (EMI), and General Maladaptive Index (GMI). Each index has a mean of 0 at any age. Negative scores indicate greater maladaptive behaviors.

“Validity is an indication that a test functions consistent with its stated purposes” (Bruininks et al., 1996, p. 137). Several studies were conducted where individuals were matched using age, gender, and whenever they were able, community
of residence criteria. On the Problem (Maladaptive) Behavior subscale, individuals with moderate to severe retardation and those with behavior disorders exhibited significantly greater amounts of problem behavior than those that were used in comparison without disabilities (Bruininks et al.). According to the SIB-R Scales of Independent Behavior-Revised Comprehensive Manual, validity is within an acceptable range (Bruininks et al.).

“Reliability of a test may be defined as the ratio of true score variance to observed score variance” (Bruininks et al., 1996, p. 114). Reliability statistics used in the SIB-R were calculated for their intended use across all subscales. “The calculation of reliability statistics used data from the 2,182 individuals in the SIB-R norming sample. Reliabilities for all subscales were calculated using the split-half procedure and corrected by the Spearman-Brown formula” (Bruininks et al., p. 119). Test-retest reliability of Maladaptive Behavior Indexes range between .83 to .88 (Bruininks et al.).

Parent Handbook

The Parent Handbook (King-Perry & Wilder, 2004) contains basic ABA and PBS principles and is written in parent terms so that it can easily be used as the structure for the behavioral education. It was used for teaching parents basic PBS. These lessons include: identifying setting, discerning the antecedent, determining the function of the problem behavior, maintaining consequences, developing an alternative competing behavior with consequences, and positive reinforcement. The handbook also provides instruction on how to write a behavioral plan.

Setting. The setting is defined as the place where the child’s challenging or
problem behavior takes place (Horner, O’Neill, & Flannery, 1997). The setting may include home, school, or another place in the community. The parents were asked to identify the setting where their child’s problem behavior most often happens, working on one setting at a time. Parents decided the one setting they wanted to target first. As the child’s behavior improved, the settings were systematically expanded to facilitate generalization across settings.

**Antecedent.** The antecedent may be defined as what happens right before the problem behavior is manifested, or the trigger of the problem behavior. Parents were asked to examine and record what happened directly before their child’s problem behavior occurred.

**Problem behavior.** The problem behavior is defined in measurable and observable terms. What was the specific problem behavior the parents wished to change? Parents were taught how to identify one problem behavior at a time, define, and write the behavior in measurable and observable terms.

**Function of the behavior.** The function of the behavior may be defined using four basic categories. These include: communication, acknowledgement, sensory needs, and escape (Jerome & Mukamal, 2000). The parent ascertained the function of their child’s problem behavior.

**Maintaining consequences.** Maintaining consequences are defined as the effect of the behavior. To determine the maintaining consequences of their child’s problem behavior, parents were asked, “What happens immediately after the behavior?” “Behaviors maintained by obtaining desirable things are examples of positive
reinforcement; behaviors maintained by escaping or avoiding undesirable things are examples of negative reinforcement (O’Neill et al., 1997, p. 12). The parents determined and recorded the positive and negative consequences of their child’s problem behavior.

Alternative competing behavior. Alternative behavior is defined as the behavior that will be used to replace the problem behavior. Competing behaviors include behaviors that cannot physically occur at the same time the child is displaying the problem behavior. Using the behavioral education, graduate students taught parents that they could help their children decrease problem behavior by using the following strategies:

1. Make the problem behavior irrelevant. Decrease or eliminate the need to engage in the behavior.

2. Make the problem behavior inefficient. Provide the child with a replacement behavior that services the same function as the inappropriate behavior.

3. Make the problem behavior ineffective. Do not allow the child to obtain what he or she wants through inappropriate behavior. (Crone & Horner, 2003. p. 13)

With direction from the graduate students, parents selected and recorded one alternative competing behavior for their child.

Consequences and reinforcement of alternative competing behavior.

Consequences are the positive and negative results of the behavior. Consequences and reinforcement of the alternative behavior are defined as what will happen immediately after the alternative competing behavior to positively reinforce the acquisition of the alternative behavior. Researchers (O’Neill et al., 1997) reiterate the importance of
selecting rewards for appropriate behaviors that are equal to or that exceed the rewards the child receives for the problem behavior. Parents selected positive consequences for the alternative competing behavior.

Behavioral support plan. Parents and BYU graduate students developed behavioral support plans for the child. The behavioral support plans followed PBS principles that the graduate students had been trained to use through PBS course work. The Habilitation and Adaptive Behavior Development Guidelines, Utah State Department of Human Services, DSPD, developed by The Division of Services for People with Disabilities Human Rights Committee, was used as a required guide in creating appropriate behavior plans.

Dr. Lynn K. Wilder reviewed each behavior plan before the parents signed the behavior support plan and before the behavior support plan was implemented. Behavior interventions emphasized positive approaches, creating adaptive behaviors as supported by the DSPD agency. The behavior support plans included no corporal punishment, electric devices of other painful stimuli, as well as no meals being denied strictly adhering to the DSPD Behavioral Supports rule number R539-6-12 4th edition policy manual.

The Habilitation and Adaptive Behavior Development Guidelines, Utah State Department of Human Services, Division of Services for People with Disabilities, Developed by: The Division of Services for People with Disabilities Human Rights Committee, August 1994, manual provided the guidelines for the behavioral interventions. It is constructed using a three level system. Level I interventions do not
require Human Rights Review, are positive intervention procedures, and include instructional or task conditions. Examples of Level I interventions include teaching functionally equivalent behavior and using primary reinforcers. Level II interventions require only the approval of the Provider Human Rights Committee Review, are mildly aversive procedures, and include non-exclusionary time outs. Level II interventions include application of mildly noxious stimuli and response cost. Level II interventions require review and approval from the Provider Human Rights Committee prior to implementation, and are moderately aversive procedures. Level III interventions include isolationary time out and deprivation of sensory stimuli. This study only used Level I behavior interventions.

Procedures

DSPD generated a mailing list from the reported 165 families, on the Family Support Immediate Needs List in Utah County (Leaver, personal communication, July 31, 2003). Only families with children that have disabilities and problem behavior ages four through sixteen were included in this study. These families had already been interviewed and ranked (according to needs) by DSPD intake coordinators.

DSPD intake coordinator, Tiffani Ortega, contacted each family in Utah County on the mailing list by mail. The letter contact contained an introductory letter (Appendix A) and a letter of consent for participation form (Appendix B) that further elucidated the research study and gave the family an opportunity to participate in this study. Interested families were invited to sign and return the Consent for Participation form in an enclosed self-addressed stamped envelope. The Consent and Participation
form included a section for the parents or guardians to write their child’s name, age, and signature, stating their desire and consent to participate in this study. This form gave the name and phone number of the project director to contact if they had any concerns or questions regarding the study.

The form also stated that signing and returning the letter did not guarantee that the family would be chosen to participate in the study. Whether families chose to participate in this study or not did not affect their placement positively or negatively on the DSPD Family Support Immediate Needs Waiting List.

The families that returned their forms were placed on a list at the DSPD office. Families were then chosen to participate in the study by Alan Tribble, State Behavior Specialist, Utah DSPD. He selected families according to age, home placement, and the perceived potential to make a positive impact on the family and child with disabilities and problem behaviors during the time frame of a ten-week program.

Alan Tribble provided a confidential list of possible families to participate in this study to Dr. Lynn K. Wilder and Karolyn King-Peery. The list included twenty-four families, four of whom Alan Tribble did not feel were qualified to participate in the study, two families that did not meet the age qualifications, and one family that when contacted asked to be removed from the study because the child was no longer exhibiting any problem behavior. From this list, graduate students at Brigham Young University (BYU) in the Counseling Psychology, and Special Education Department (CPSE) were randomly assigned one family.

Parents were given the option of contacting Dr. Lynn K. Wilder or Karolyn
King-Peery with any concerns they had throughout the study. Concerns that could not be resolved through consultation were referred to Alan Tribble. Alan Tribble, Dr. Lynn Wilder, and Karolyn King-Peery made two case-by-case decisions—the first regarding suspected child abuse and the second concerning fears of the child contemplating suicide. A collaborative effort was made to ensure the study was a positive and productive experience for all individuals participating.

Parents were not penalized for not completing the program. However, those parents that completed the program received a $25 gift certificate to a local restaurant, and two $10 gift certificates to Walmart for collecting data on the problem behavior and then on the alternative replacement behavior. All families that began the study completed the study.

This study could not serve all families that returned the participation form, because of the limited number of graduate students and eligibility requirements. From the list of those who returned the form, families were randomly selected to participate. The number of families that participated depended on the number of graduate students enrolled in CPSE 610, the course that currently administers this project.

CPSE graduate students called their assigned families and scheduled an interview. During the initial interview phase the graduate students got to know the family by completing a qualitative Confidential Parent Survey (Appendix C) as an entrance interview, and administered the PCRI, and the SIB-R behavior protocol to learn more about the child’s problem behavior. The information from the PCRI and the SIB-R was used as baseline data. After parents received the behavioral education, CPSE
graduate students administered the PCRI and SIB-R posttests for data. CPSE graduate students also gave a qualitative Confidential Parent Survey as an exit interview. After each visit, the graduate student wrote a brief summary about the home visit on an anecdotal log (Appendix D) and had the parent sign it. At the end of the study, anonymous surveys were completed by parents (Appendix E) and graduate students (Appendix F) to address the social validity of the study. All behavior support plans were approved by Dr. Lynn K. Wilder, and were signed by the parent before they were implemented.

Data Analysis Procedures

The data that were collected for this project were ratings in the Limit Settings and Parental Support subscales of the PCRI and the Problem Behavior subscale of the SIB-R. Pre- and posttest ratings were compared using Paired t tests.

All raw data from this study was confidential and only available to the researchers, DSPD participating employees, and participating BYU CPSE graduate students.

CPSE graduate students met weekly for class instruction, discussion, and support in the behavioral education components of writing a FUBA and developing a behavior support plan. Alan Tribble was a guest speaker, and provided added instruction and feedback for graduate students as they prepared to help parents write the FUBA and behavior plans as part of the behavioral education.

Parents learned how to use PBS principles to identify the function of their child’s problem behavior. The behavioral education consisted of PBS principles of
determining setting events, identifying an antecedent, describing the problem behavior, and recognizing maintaining consequences of their child’s behavior. Graduate students and parents used the parent handbook as a guide throughout the problem solving process. As part of the behavioral education, CPSE graduate students and parents wrote the function of their child’s problem behavior FUBA. Using the FUBA, parents choose an alternative competing behavior, identified consequences and choose positive reinforcement for the alternative competing behavior. Together the CPSE graduate students and parents wrote a behavior plan that lowered the incidence of problem behavior and increased the alternative competing behavior.

*Social Validity*

Graduate students gave each parent participating in the research a parent survey on their last visit. The survey was anonymously and independently completed by the mothers and mailed to the researcher using a self-addressed stamped envelope. The survey allowed parents the opportunity to express their feelings regarding the training in functional behavior analysis and developing behavior plans, and working with their graduate student.
CHAPTER IV
RESULTS

The following questions were used to guide this study.

1. What are the differences in pre and post ratings of problem (maladaptive) behavior and the behavior’s frequency and severity on the Scales of Behavior-Revised (SIB-R) as rated by mothers?

2. What are the differences in pre and post ratings on the Limit Setting subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?

3. What are the differences in pre and post ratings in parental support on the Support Subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?

Analysis of Study Questions

Pre and post SIB-R and PCRI assessments were administered to 17 families from the DSPD Family Support waiting list. The SIB-R and PCRI assessments were given before and after the families completed the behavioral education. Seventeen mothers completed a SIB-R assessment, one assessment per household in the study. Seventeen mothers with nine fathers completed the PCRI assessment. Eight mothers completed one PCRI assessment per household, and nine mothers and fathers completed two PCRI assessments, two per household (one mother, one father). The mothers were the predominant source of assessment information as primary caretakers of their children with disabilities and problem behaviors. All families that were involved in the behavioral education completed pre and post assessments.
Question 1: What are the differences in pre and post ratings of problem (maladaptive) behavior and the behavior’s frequency and severity on the Scales of Behavior-Revised (SIB-R) as rated by mothers?

To answer the first study question, the pre and post SIB-R Maladaptive Problem Behavior ratings were analyzed using a two-sample paired t test (see Table 1). The 16 different tests were investigated using a family alpha equal to .05, individual alpha equal to .0032, with an overall chance of error at 5% for a Type I error.

One SIB-R was administered for each child. Mothers reported that the behavioral education significantly reduced the severity in two of the eight areas. Mothers reported that the severity of their child’s withdrawal or inattentive behaviors and uncooperative behaviors significantly decreased. Withdrawal or inattentive behaviors includes behaviors such as “being around others or paying attention—for example, keeping away from other people, expressing unusual fears, showing little interest in activities, appearing sad or worried, showing little concentration on a task, sleeping too much, or talking negatively about self” (p. 19). Uncooperative behaviors include behaviors such as “behavior that is uncooperative—for example, refusing to obey, do chores, or follow rules; acting defiantly or pouting; refusing to attend school or go to work; arriving late at school or work; refusing to take turns or share; cheating; stealing; or breaking laws” (p. 19).

Mothers’ responses to withdrawal or inattentive behaviors and uncooperative behavior severity cross-tabulation illustrates that a significant number of mothers rated a decrease in the severity of problem behaviors associated within the two categories of
problem behaviors. Mothers’ responses to withdrawal and inattentive behaviors demonstrated a general trend of decrease in severity, with no statistical outliers, and no reports of increased withdrawal or inattentive behaviors. Mothers’ responses to uncooperative behaviors indicated that one mother reported a dramatic decrease in severity of uncooperative behavior, and one mother indicated that the child’s severity increased in uncooperative behavior. Overall, mothers’ reported a decrease in the severity of withdrawal or inattentive behaviors and uncooperative behaviors (Table 1).

Cross-tabulation may be used to illustrate the rating change from one level of behavior severity to the next, from pre to post (see Tables 2 and 3).

Table 1

*Means on the Maladaptive Problem Behavior Section of the SIB-R Pre- and Posttests*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest</th>
<th>Posttest</th>
<th>$t$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hurtful to Self-Frequency</td>
<td>1.94</td>
<td>2.18</td>
<td>-0.94</td>
</tr>
<tr>
<td>Hurtful to Self-Severity</td>
<td>0.88</td>
<td>0.82</td>
<td>0.212</td>
</tr>
<tr>
<td>Hurtful to Others-Frequency</td>
<td>1.94</td>
<td>1.71</td>
<td>0.454</td>
</tr>
<tr>
<td>Hurtful to Others-Severity</td>
<td>0.88</td>
<td>0.53</td>
<td>2.073</td>
</tr>
<tr>
<td>Destructive to Property-Frequency</td>
<td>1.82</td>
<td>1.24</td>
<td>1.532</td>
</tr>
<tr>
<td>Destructive to Property-Severity</td>
<td>0.94</td>
<td>0.63</td>
<td>1.321</td>
</tr>
<tr>
<td>Disruptive Behavior-Frequency</td>
<td>2.82</td>
<td>2.76</td>
<td>0.122</td>
</tr>
<tr>
<td>Disruptive Behavior-Severity</td>
<td>1.41</td>
<td>0.94</td>
<td>1.926</td>
</tr>
<tr>
<td>Unusual or Repetitive Habits-Frequency</td>
<td>3.29</td>
<td>3.24</td>
<td>0.160</td>
</tr>
<tr>
<td>Unusual or Repetitive Habits-Severity</td>
<td>1.18</td>
<td>0.88</td>
<td>1.098</td>
</tr>
<tr>
<td>Social Offensive Behavior-Frequency</td>
<td>1.71</td>
<td>1.35</td>
<td>0.859</td>
</tr>
<tr>
<td>Social Offensive Behavior-Severity</td>
<td>1.18</td>
<td>0.35</td>
<td>2.865</td>
</tr>
<tr>
<td>Withdrawal or Inattentive Behavior-Frequency</td>
<td>3.19</td>
<td>2.63</td>
<td>1.781</td>
</tr>
<tr>
<td>Withdrawal or Inattentive Behavior-Severity</td>
<td>1.88</td>
<td>0.88</td>
<td>3.873*</td>
</tr>
<tr>
<td>Uncooperative Behavior-Frequency</td>
<td>3.12</td>
<td>2.71</td>
<td>1.692</td>
</tr>
<tr>
<td>Uncooperative Behavior-Severity</td>
<td>1.94</td>
<td>1.19</td>
<td>3.503*</td>
</tr>
</tbody>
</table>

* significant with a family alpha of .05
Table 2

Cross-Tabulation of Number of Responses to Severity of Withdrawal or Inattentive Behavior

<table>
<thead>
<tr>
<th>Variable categories of responses before treatment</th>
<th>Categories of responses after treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0—Not serious; not a problem</td>
</tr>
<tr>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
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<tr>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 3

Cross-Tabulation of Number of Responses to Severity of Uncooperative Behavior

<table>
<thead>
<tr>
<th>Variable categories of responses before treatment</th>
<th>Categories of responses after treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0—Not serious; not a problem</td>
</tr>
<tr>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
</tr>
</tbody>
</table>

Two parents from the study wrote anonymously, “we were able to focus on a particular problem behavior and decrease the frequency of that behavior,” and “[graduate student’s name] helped me to get back on track—to overcome my fears of failure.”
Question 2: What are the differences in pre and post ratings on the Limit Setting subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?

To answer the second study question, pre and post PCRI Limit Setting assessment was analyzed using a two sample paired t test (see Table 4). PCRI Limit Setting includes 12 statements such as “My child is more difficult to care for than most children are,” and “My child is out of control much of the time” The 12-statement subscale total was investigated using a family alpha equal to .05, individual alpha equal to .0032, with an overall chance of error at 5% for a Type I error.

The analyzed results show a significant difference in before and after mothers’ Limit Setting totals (pretest: 1.94; posttest). A low limit setting suggests that the parent may feel angry, that the situation in the home may be out of control, and that the child may feel that discipline may be inconsistent or possibly even hostile (Gerard, 1994). Mothers’ results of the pre and post Limit Support PCRI assessment ratings indicate that mothers agreed with the negative statements before the behavioral education and then disagreed with the negative statements after completing the behavioral education.

Table 4

Mothers’ and Fathers’ Mean Gain from PCRI

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest mean</th>
<th>Posttest mean</th>
<th>t</th>
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</thead>
<tbody>
<tr>
<td>Mother’s LS score</td>
<td>2.32</td>
<td>2.49</td>
<td>-3.096*</td>
</tr>
<tr>
<td>Father’s LS score</td>
<td>2.40</td>
<td>2.48</td>
<td>-1.029</td>
</tr>
<tr>
<td>Mother’s SP score</td>
<td>2.12</td>
<td>2.30</td>
<td>-2.167</td>
</tr>
<tr>
<td>Father’s SP score</td>
<td>2.15</td>
<td>2.27</td>
<td>-1.273</td>
</tr>
</tbody>
</table>

* significant at a family alpha .05
The following histogram illustrates the differences of the increase between the two means post to pre. For example three mothers’ differences of the increase between the two means post to pre were 0.00 to 0.10. The father’s results indicate that a larger sample size was needed to demonstrate any significant difference in pre- and post-PCRI Limited Support assessment (see Figure 1).

Two parents from the study anonymously answered the question: “By working with us to form a consistent response to the behavior and help us to develop alternatives

![Figure 1. Histogram of increase in mothers’ LS rating from PCRI.](image)
to prevent the behavior from occurring,” and “To hang in there and keep working and you’ll see results.”

**Question 3: What are the differences in pre and post ratings in parental support on the Support Subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers?**

To answer the third study question, the pre and post PCRI Parental Support assessment was analyzed using a two sample paired *t* test. The Parental Support questions had six questions negatively written such as “My life is very stressful right now” and “I sometimes feel overburdened by my responsibilities as a parent”. Three questions positively written such as “I get a great deal of enjoyment from all aspects of my life.”

Positively written questions were reverse coded so as to make the mean PCRI support scale meaningful. Low ratings on the Parental Support scale suggest that parents feel seriously overburdened, and may be experiencing high levels of stress. PCRI Parental Support ratings on the nine items were summed to create a total score, which was investigated using a family alpha equal to .05, individual alpha equal to .0032, with an overall chance of error at 5% for a Type 1 error.

The analyzed results showed little difference in pre and post mothers’ PCRI Parental Support totals, with a mean of -.17647 at a 98.3% confidence interval of the difference lower being -.39337 and upper being .04043. Looking statistically at the low *p* value implicates that an increased sample size would suggest a more significant increase the Parental Support scale. Father’s pre and post PCRI Parental Support results
indicate little difference in ratings before and after the behavioral education. This may be due to the small sample size.

The result of the Parental Support subscale is consistent with the Utah State Family Council’s Chairpersons statement that “These families…are in very critical and desperate situations” (Bowman, letter of support, October, 2002).

One parent from the study anonymously wrote: “[the graduate student helped us by] explaining the tools that we could use to evaluate and track problem behavior. Let us vent and discuss stress that the problem behaviors have caused.”

Summary

Mothers indicated a significant difference in pre and post SIB-R Maladaptive Problem Behavior in Withdrawal or Inattentive Behavior and in Uncooperative Behavior scales after completing the behavioral education. Mothers’ responses indicated designate a significant difference in pre and post PCRI Limit Setting after completing the behavioral education. Using an increased sample size, PCRI Parental Support ratings may indicate a significant difference after receiving the behavioral education. Fathers’ responses showed no significant change in pre and post SIB-R Maladaptive Problem Behaviors, and pre and PCRI Limit Setting and Parental Support largely due to small sample size.

Parents were appreciative of the behavioral education. One parent that participated anonymously wrote: “She gave us some great ideas, and most of all a sounding board, encouragement, and motivation.”
CHAPTER V
DISCUSSION

The purpose of this study was to examine the effects of graduate students providing PBS behavioral education to parents who have children with disabilities and problem behaviors on the Utah DSPD Family Support waiting list. Would behavioral education decrease maladaptive problem behaviors as indicated on the SIB-R assessment for children participating in this study? Yes. The severity of Withdrawal and Inappropriate Behaviors and Uncooperative Behaviors decreased. Would the behavioral education decrease parent’s perceptions of their ineffective disciplining techniques? Yes. Parents indicated that their ability to appropriately deal with their child’s problem behavior increased. Would parents feel greater levels of support as indicated on the PCRI Parental Support? Not yet. The parents participating in this study indicated that more support is still needed. One parent anonymously wrote, “This was very helpful to us…. This helped keep us focused, encouraged and determined. This is the only intervention we have at home and it has been so very helpful to us. (We’re on the DSPD waiting list and see no end to that!).”

Decreasing Maladaptive Problem Behavior

Researchers (Fox et al., 2002) noted that the problem behaviors demonstrated by a child with disabilities negatively impacts all members of the family system, and that the longer the problem behaviors continue, the more pervasive their influence becomes.

Parental stress was greater as a result of difficult behaviors of their child with disabilities than from the specific type of disability; this effect was found for measures of stress specifically related to the presence of difficult child behaviors.
and problems managing the child, as well as stress associated with disruption in activities and opportunities for other family members. (Floyd & Gallagher, 1997, p. 369)

The impact of problem behaviors is not only noted in research literature but is also seen by those working in family support positions in Utah. Deborah Bowman, Chair of the State Family Council, wrote concerning the grave needs of families on the DSPD Family Support waiting list “These families have been put on a ’waiting list’ for services and many are in very critical and desperate situations. From our experience, one of the most sought after supports for families with children and adults with disabilities is help with behavior issues” (Bowman, State Family Council Support Letter, 2002).

Increasing Parents’ Abilities to Appropriately Work with Their Child’s Problem Behavior

“Interventions must do more than build on family strengths: They must be consistent with, and embedded in, the everyday business of family life. Thus, assessments that precede intervention planning must address a wide range of characteristics describing child and family functioning” (Bernheimer & Keogh, 1995, p. 416). PBS principles created the foundation of the behavioral education for this study. PBS recognizes that the family has expertise when it comes to knowing their child, and their child’s disability, and by focusing on understanding the child’s problem behavior by using functional assessment. PBS stresses effective behavioral supports that are a good contextual fit with family life (Lucyshyn et al., 2002).
Parents and CPSE graduate students worked through a handbook that was developed specifically for this study. The handbook was written as a short workbook with parent friendly language. Research reports that parents desire that written information be brief and readable (Ruef & Turnbull, 2001). The handbook was developed to be used as a guide, helping families and CPSE graduate students determine the function of the problem behavior and write a behavior plan for the child. One parent anonymously wrote, “The explanations were clear and easy to understand. The charts were very helpful.”

Parental Support

Families with children with disabilities may experience high levels of family stress, which may be amplified by their child also having high levels of maladaptive, problem behaviors (Hodapp, Wizma, & Massino, 1997). PBS principles “encourages parents to work with professionals as equal partners, to develop a vision of a more successful life for their child with a disability, and to become experts in their own right in using behavioral supports to improve child behaviors and improve the quality of family life (Lucyshyn et al., 2002, p. 36). Not all problem behaviors need to be eliminated to improve family stress levels (Sofronoff & Fabotko, 2002). By providing support for families with children with disabilities and problem behaviors, parents’ feelings of stress may decrease. Parents “who perceive themselves as getting enough emotional and practical support are in a better position to provide adequate care to a child than those who do not” (Gerard, 1994, p. 50).
Limitations

This study was the first collaborative effort between the DSPD and BYU’s Department of Counseling Psychology and Special Education (CPSE) and funded by a BYU Family Studies Grant. DSPD is a State program that is part of the Department of Human Services, and BYU is a private religious university. Building a positive collaborative relationship required two years of dedication, communication, and compromise between Alan Tribble, DSPD state Behavior Analyst, Dr. Lynn K. Wilder, Associate Professor, and Karolyn King-Peery at BYU.

The State Human Services Internal Review Board (IRB) deliberated for over a year, revising and reworking the study’s State IRB proposal. Finally, the IRB proposal was accepted with revisions and strict provisions. While the researchers anticipated using a control group, the State IRB felt that it would not be fair to make some families who had already waited so long for support unable to participate because of control group placement.

The statistics of this study would have been stronger using a control group study design and an increased sample size. The number of graduate students enrolled in the class determines the sample size of the study. Fortunately, because of the support of Dr. Tina T. Dyches and Dr. Mary Anne Prater, administrators in the CPSE department, this research will continue into the future. It is hopeful that through on-going collaboration, further studies will be able to use a control group design, and the sample size will continue to increase each year.
Future Research

Graduate students and families may benefit from ongoing research in this area. Researchers (Lucyshyn et al., 2000) recommend that graduate programs, in addition to training knowledgeable and competent professionals, should also provide instruction that values the skills that will be necessary to build collaborative partnerships with families and other professionals. Families face many potential obstacles in maintaining the behavioral education skills that they have learned. Researchers (Hieneman, & Dunlap, 2001; Lucyshyn et al., 2002) recommend that practitioners and service agencies plan and implement family maintenance programs and longitudinal support similar to a “dental model” or ongoing periodical support.

One parent anonymously wrote, “. . . This was very helpful to us. I wish we could have a student work with us each semester. Thank you also for the gift cards and Los Hermanos certificates. You really didn’t have to do that. [Graduate student’s] help was gift enough for us!”

Conclusion

The little blond boy is now 18. He is one of only a few young men with his syndrome living in Utah and still living in a family setting. Typically his syndrome is linked to aggressive problem behaviors that make home placement difficult, especially for young men. As Matthew’s parent, I believe that his continued home placement is the result of behavioral education emphasizing PBS principles I have received in the past and continue to receive. Matthew seldom has problem behaviors, making it possible for my family to eat in restaurants, watch high school sports, go to movies, and
participate in religious activities. The Family Studies Center Grant that funded this research accentuates the study’s potential for improving family life consistent with the principles of “The Family, A Proclamation to the World.” The Proclamation document states, “Parents have a sacred duty to rear their children in love and righteousness, to provide for their physical and spiritual needs, to teach them to love and serve one another, to observe the commandments of God and be law abiding citizens wherever they live.” Behavioral education and family support has made it possible for my family, a family that has a child with disabilities and problem behaviors, to reach for this standard. Continued research, using larger sample sizes is encouraged. At a time when State resources are minimal, in comparison to what is needed, collaborative projects such as this one may help provide some support services for families that have children with disabilities and problem behaviors.
REFERENCES


Wilder, L. K., King-Peery, K., Dyches, T. T., Bowman, P., Tribble, A., & Morse, F. (2002). *Mom, catch me a rainbow: Improving family life for families of children with disabilities by teaching parents to deal effectively with inappropriate behaviors (Family Studies Grant)*. Provo, UT: Brigham Young University, Department of Counseling Psychology and Special Education.
Appendix A

Participation Letter and Consent Form
Participation and Consent To Be a Research Subject

The purpose of this research is to provide parent training by graduate students in Counseling/Psychology and Special Education, which teaches parents how to design and implement effective behavior plans for their child with disabilities and difficult behaviors. We will look at whether receiving this parent training helps lower problematic behavior and family stress levels. This research is also partially being conducted to fulfill the requirement of Karolyn King-Peery’s graduate thesis, and is being paid for by a Family Studies Center grant. You have been chosen to participate in this study because of your placement on the DSPD Family Support waiting list. This study may provide some supports while you are waiting, and has no affect upon your placement on the waiting list.

You will be trained to use the Applied Behavior Analysis to help you encourage your child’s good behavior. This program emphasizes positive interventions. You will be assigned a graduate student in Counseling/Psychology or Special Education (CPSE) programs at Brigham Young University that has been trained in this program, and who will be responsible to complete assignments for their graduate class that correspond with this project. In your home or at the CPSE McKay Building consultation rooms, the graduate student working with you will begin by meeting with you and completing a pre-interview using a behavior inventory, that will help the graduate student and you determine the behavior’s you would like to work on with your child. The behavior inventory will also help you see the improvement your child makes after you and your assigned graduate student have developed and implemented you child’s behavior intervention plan. They will provide support for you as you learn new skills, working with you for at least one hour a week for eight to ten weeks. Karolyn-King Peery, project director, Dr. Lynn Wilder, project coordinator, and Alan Tribble, DSPD State Behavior Specialist, will also be available to help your assigned graduate student and your family as you acquire these parenting skills. The graduate student will conclude this research project by giving a post-interview at the end of the eight to ten weeks using the same behavior inventory given during the pre-interview to help measure progress. The pre- and post- interviews will take about one hour each to complete.

As graduate students work with your family they will be careful to work as professionals, respecting your rights of confidentiality. However, “Utah law requires us to report any suspected or actual abuse, neglect, or exploitation of a child, or an adult who has a mental or physical impairment which affects that person’s ability to provide for or protect him/herself. If the researcher or graduate student has reason to believe that such abuse, neglect, or exploitation has occurred, the researcher or graduate student will report this to Child Protective Services (CPS), Adult Protective Services (APS) or to the nearest law enforcement agency.” There are few risks with the study. However, sometimes when family members answer questions regarding various aspects of family life, unpleasant memories or frustrations may be recalled. If you have concerns regarding the graduate student assigned to you or the designed behavioral intervention, you may call Dr. Wilder, Project Coordinator (422-3857) or Karolyn King-Peery, Project Director (465-8884). By participating in this research, your family will have the benefit of increased knowledge in appropriate and effective behavior interventions, help in designing individual behavior plans for your child, and support implementing these plans for your child.

The Division of Services for People with Disabilities (DSPD) will also provide limited support. Alan Tribble, State Behavior Specialist will be available for situations that become too difficult for graduate students to resolve. He supports this project and has been a valuable advocate for the families on the DSPD Family Support list.

Participation is voluntary and you may withdraw at anytime without penalty or loss of benefits. It will also not effect your standing on the waiting list. Fifteen to twenty-five families will be randomly chosen to participate in this research; therefore, there may be a chance that your family will not be selected. If you are not selected for this study, you will continue to wait for DSPD Family Support services. If you are chosen to participate, in appreciation for your involvement and completion of the research study, you will receive a $20.00 certificate to be used at a local restaurant.

If you have any questions regarding this project please contact:

Lynn Wilder, Ed.D
322-F McKay School of Education
Brigham Young University
Provo, UT 84605
If you have questions regarding your rights as a research subject or rights as a participant in this research project, you may contact:

Mary Caputo, M.P.A  
Chair of Human Rights Committee  
Bureau of Internal Review & Audit  
Salt Lake City, Utah  
(801) 538-4295

Dr. Shane Schulthes  
Chair of Human Rights Committee  
Bureau of Internal Review & Audit  
Salt Lake City, Utah  
(801) 538-4295

By signing this consent form, you are acknowledging that you have read the information above and have been given the opportunity to ask any questions you may have concerning this research project, and desire to participate in this research study.

Signature: _______________________________ Date: _______________________________

Individual with disabilities name: ________________________ Age: __________________

*Please return consent form in self-addressed stamped envelope.
Appendix B
Parent Letter
September 2004

Dear Parent,

You have been chosen for the opportunity to participate in a study. This study will help you more effectively work with your child’s disability and problem behavior.

I am a mother of a child with disabilities. I have received DSPD Family Support for three years. My family was on the waiting list for five years. Five years can be a long time without the support we need to take good care of our children. I am now a graduate student at BYU, and I am inviting you to participate in a research project. I am doing this research, in part, for my graduate thesis. The purpose of this research is to teach parents how to help their child with disabilities have less problem behavior. We will also look at whether this helps lower family stress levels. Dr. Wilder, a professor at BYU in the Counseling/Psychology and Special Education (CPSE) department, has written and received a grant to help fund this research. We have also worked with Alan Tribble, State DSPD Behaviorist Specialist, to make this research possible.

Each participating family will be assigned a graduate student in Counseling/Psychology or Special Education programs at Brigham Young University that have been trained in Applied Behavior Analysis and Family Consulting. The graduate students will be completing class assignments as they teach you how to implement these behavior programs in your home and provide support for you as you learn these new skills, working with you for at least one hour a week for eight to ten weeks. Karolyn-King Peery, project director, Dr. Lynn Wilder, project coordinator, and Alan Tribble will also be available to help your assigned graduate student and your family as you acquire these parenting skills.

Your confidentiality will be honored. As graduate students work with your family, they will be careful to work as professionals, respecting your rights of confidentiality. There are no perceived risks for your family. There is no loss of benefits to which you are otherwise entitled, and your participation will have no impact (either positive or negative) on your services or placement on the Family Support waiting list. If you have concerns regarding the graduate student assigned to you or the designed behavioral intervention, you may call Dr. Wilder, Project Coordinator (422-3857) or Karolyn Peery, Project Director (465-8884). By participating in this research, your family may have the benefit of being able to help your child with disabilities have less challenging behavior.

Participation is voluntary and you may withdraw at anytime without penalty. Participating will not affect your standing on the Family Support waiting list. Families that have children four to sixteen and living at home will be able to apply. Not all families that apply will be selected to participate. DSPD is mailing this letter and consent form to you. DSPD has not given us any individual or family names, addresses, or any other personal information. Also, we will not receive or have access to any personal information from DSPD unless you agree to participate in this research. Fifteen to twenty-five families will be chosen to participate. DSPD will notify you if you are selected for this research. In appreciation you will receive a small certificate to be used at a local restaurant or shopping center after completing the research.

If you would like to participate please complete and send the enclosed participation and consent form. We need to have you reply quickly by September 21, 2004. If you have any questions please call either:

Lynn Wilder, Ed.D
322-F McKay School of Education
Brigham Young University
Provo, UT 84605
(801) 422-1237

Or me, Karolyn King-Peery

(801) 465-8884
Thank you! Karolyn Peery
Appendix C
Confidential Parent Interview
Confidential Parent Interview
Only answer questions that you feel comfortable talking about.

Interviewer: ________________________ Date: _____________________
Person being interviewed: ________________________________

<table>
<thead>
<tr>
<th>Personal Information</th>
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<td>Parent’s names: ____________________________</td>
</tr>
<tr>
<td>Address: ____________________________</td>
</tr>
<tr>
<td>Phone: __________________________</td>
</tr>
<tr>
<td>Child’s birth date: ___________________</td>
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<tr>
<td>Child’s age: ___________________</td>
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<tr>
<td>Child’s school: ___________________</td>
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<table>
<thead>
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<tr>
<td>Reason for wanting to participate: __________________________</td>
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<tr>
<td>What do you hope to gain from this experience? __________________________</td>
</tr>
<tr>
<td>What will make this experience feel successful for you? __________________________</td>
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<tr>
<td>Comments: __________________________</td>
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### School Information

<table>
<thead>
<tr>
<th>Classroom setting:</th>
<th>General Ed Classroom</th>
<th>Resource Classroom</th>
<th>Special Ed Classroom</th>
<th>Special School</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does your child get to and from school?</td>
<td>Bus</td>
<td>Parent Ride</td>
<td>Walk</td>
<td>Special Bus</td>
</tr>
</tbody>
</table>

### Behavior Information at School

**What do you feel has worked at school?**

______________________________

______________________________

**What do you feel has not worked at school?**

______________________________

______________________________

**How do you feel about your child’s behavior at school?**

______________________________

**Do you think that your child’s behavioral needs are being met at school?**

______________________________

______________________________

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**What has been used at school to reward good behavior?**

______________________________

**What consequences have been used at school for problem behavior?**

______________________________

---

### Family Information

**List all family members:**

<table>
<thead>
<tr>
<th>Names</th>
<th>Age</th>
<th>Relationship</th>
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<tbody>
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</tbody>
</table>

**What family members live at home?**

______________________________

---

**Current Marital Status?**

______________________________

**Family Support Systems?**

Extended Family | Religious Groups | Neighbors | Professionals

**Primary language used in the home?**

______________________________
## Developmental History

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>At what age did your child crawl?</td>
<td>_______</td>
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<tr>
<td>Walk?</td>
<td>_______</td>
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<tr>
<td>Become Toilet Trained?</td>
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<tr>
<td>List recent illnesses, accidents or hospitalizations:</td>
<td>_______</td>
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<tr>
<td>List recent illnesses, accidents or hospitalizations:</td>
<td>_______</td>
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<tr>
<td>Seizures, convulsions? (frequency/severity)</td>
<td>_______</td>
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<td>Hearing:</td>
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<td>Health issues:</td>
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<td>Disability Category?</td>
<td>_______</td>
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<tr>
<td>Medications?</td>
<td>_______</td>
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<tr>
<td>Child’s primary form of communication?</td>
<td>_______</td>
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<tr>
<td>Other:</td>
<td>_______</td>
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</tbody>
</table>
### Looking at Family Stress

0-Not stressful  
1-Minimal stress  
2-Moderate stress  
3-Stressful  
4-High levels of stress  

**To you, how stressful is:**

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
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<td>Child’s disability?</td>
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<td>Child’s problem behavior?</td>
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<td>Child’s health?</td>
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<td>Lack of family support?</td>
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<td>Lack of respite support?</td>
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<td>Marital relationship?</td>
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<td>Sibling relationships?</td>
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<td>Extended family relationships?</td>
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<td>Participation in the community?</td>
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<td>Daily care of child?</td>
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<td>Daily care of family?</td>
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<td>Stress when problem behavior happens in public?</td>
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<td>Stress when problem behavior happens with extended family?</td>
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<td>Stress when problem behavior happens at home?</td>
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<tr>
<td>Parent Survey on the Problem Behavior</td>
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<tr>
<td>1. Problem behavior causes me the most stress when:</td>
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<td>2. Does problem behavior cause stress at home with siblings, grandparents, or others? How?</td>
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<td>3. Does your child's problem behavior affect your marital relationship? How?</td>
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<td>4. Do you think that reducing your child’s problem behavior would reduce the stress you feel? How?</td>
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<td>5. What is the most difficult about having a child with disabilities and problem behavior for you?</td>
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<td>6. What is the most stressful, your child’s disability or your child’s problem behavior?</td>
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<td>7. What works for you to help you decrease feelings of stress?</td>
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<td>8. What do you think are the joys of parenting a child with a disability?</td>
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<td>Problem Behavior</td>
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<td>1. How often do you feel like you are taking care of problem behaviors?</td>
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<td>2. Do you feel the problem behavior has affected your family? How?</td>
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<td>3. How do you feel the problem behavior has affected siblings?</td>
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<td>4. How do you usually deal with problem behavior?</td>
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<td>5. What do you think is the most difficult part of the problem behavior?</td>
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</table>
Appendix D

Family Consultation Log
Family Consultation Log

Graduate Student Name: _______________________________
Parent Name: _______________________________
Child Name: _______________________________
Address: _____________________________________
_____________________________________________
Phone: _______________________________

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Progress Notes</th>
<th>GS Initial</th>
<th>Parent Initial</th>
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<tbody>
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Appendix E

Parent Survey
Parent Survey

Name:  (Optional) _________________________

1. What do you feel was the most important thing you learned while working with your graduate student?

2. How did your assigned graduate student help you the most?

3. Do you feel the parent handbook was clear and easy to follow? Why or why not?

4. Did you feel like you were able to help your child’s problem behavior? Why or why not?

5. What would you recommend to do differently to help families in the future that participate in this practicum?
Appendix F

Student Survey
Families Project 2004 Student Survey
Name: Optional

1. What do you feel was the best thing about working with your family?

2. What do you feel was the most difficult thing about working with your family?

3. What do you wish you would have know before working with the family?

4. What parts of the parent handbook did you feel were most helpful?

5. What parts of the parent handbook did you feel needed to be changed?

6. How would you suggest these changes should be made?

7. What recommendations would you give for future families projects?

8. What would have made the families project easier for you?

9. What skills and abilities did you feel you brought to this project?

10. Did you feel you were successful at accomplishing what you had hoped for the project? Why or why not?
Appendix G

BYU Graduate Student Confidentiality Agreement
BYU Graduate Student Confidentiality Agreement

As a university student participating in this practicum in the home of parents with children with disabilities and difficult behaviors, you will have access to confidential information about the family.

1. The family file you compile is to be confidential and handed into Dr. Wilder or Dr. Crook at the end of Fall Semester 2003.
2. You may not make photocopies of documents contained in your family file.
3. You must remove all names of your families and children when completing assignments for the class. You are also responsible for guarding the distribution of the finished written report.
4. While working with the family, you may not allow anyone other than BYU personnel or Alan Tribble to examine files.
5. Discussion of the family by name or by any other identifying information outside of the home or university class setting is a violation of the family’s/child’s right to confidentiality and could be subject to court action.
6. Any test results should also be treated in the above manner.

Your signature on this document will represent your agreement to refrain from inappropriate discussion of the family you are assigned. Confidentiality is your legal responsibility.

I agree to comply with these conditions.

Name: ________________________________

Date: _______________
Appendix H

Parent Handbook
Parent Handbook

Written by: Karolyn King-Peery & Dr. Lynn K. Wilder
2004
Introduction

Matthew was a beautiful little boy. He had thick blond hair and fine features. Matthew never slept, he was always on the run, he never babbled, and he began to have problem behaviors. At 15 months, Matthew’s head stopped growing. His pediatrician began running tests to see what was causing Matthew’s language and growth delays. On the Saturday morning before Thanksgiving, my husband and I walked into the doctor’s office to wait. The doctor came in and hung up his coat and sat by us. He told us that our son had the 5p- Syndrome, or the Cri Du Chat Syndrome, a severe form of mental retardation. We got into our car and started to drive home. I kept turning and looking at Matthew to see if he had changed now that he had a clinical label, but he looked the same as he always had, he was still my beautiful little boy. In just one hour our whole world changed. Where would we go now? How would we be able to effectively deal with our son’s disability and his problem behavior?

Now, nearly 17 years later, I have some answers to those questions my husband and I asked so long ago. One of the most difficult challenges we experienced revolved around the problematic behavior that resulted from Matthew’s disability. We were fortunate to work with people that gave us direction and support as we worked to decrease all kinds of behaviors including head banging, aggressiveness, and behaviors associated with puberty. The hours of dedication and hard work, because it is the hardest work we have ever done, has paid off. Matthew can go out to eat with our family and no one knows he has a disability, my husband and I can go on a “date” and have him act appropriately for a babysitter, and best of all, he can go with his cousin for a Pepsi.

This handbook is designed to help other parents learn and practice the behavior skills we were taught. It will take you step by step through the same behavior program used in schools.
The principles work just as effectively at home as they do at school. Hopefully by the time you are finished, you will understand and be able to apply the basic components of Applied Behavior Analysis (ABA) and Positive Behavior Supports (PBS). With a bit of luck, this handbook can make a difference in your home, as it has in ours.
What is Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS)?

Conceptual applied behavior analysis has promised a valuable technology based on the work done in experimental analysis of behavior (Skinner, 1974). B. F. Skinner (1904-1988) was the first researcher in behavior analysis to distinguish the operant conditioners of behavior that are concerned mostly with consequences of the behavior and the relationship between behavior and the consequences that come from the behavior (Alberto & Troutman, 1999). ABA has evolved from this beginning into something additive, Positive Behavior Support (PBS)

Identifying the Problem Behavior

What is the problem behavior that you want to work on? Think about the behaviors that cause the most disruption in your family routines or that cause the greatest amount of family stress. Choose and list two or three behaviors that you may want to work on.

Example: tantrums, yelling, pinching

Problem Behavior 1: ____________________________________________________________

Problem Behavior 2: __________________________________________________________

Problem Behavior 3: __________________________________________________________

Look at your list. What behavior would you like to work through first? Choose one from the above list and write it on the following line.

Examples: tantrums

Problem behavior to work on first: ___________________________________________________________

It is tempting to choose more than one behavior at a time to work on, especially if your child has several problem behaviors. However, you will make the most progress if you choose one at a time. When the first behavior is decreased or eliminated you can move to the next behavior you want to work on.

Look at the behavior you chose. If you were talking to have a neighbor, friend or extended family member how would you explain this behavior to them? When writing the
behavior you want to work on, think of what the behavior looks like (observable). Write the problem behavior you wish to work on first in observable terms.

Example: Tantrums look like: crying, laying on floor, pounding fist on floor and kicking.

What does the problem behavior look like in observable terms? _______________________

How often does this behavior happen? Does the problem behavior happen once or twice a week, a day, an hour or even more often than that? Estimate how often you think the behavior happens.

**Observable problem behavior happens** (circle one) weekly daily hourly

Now let's measure how often the behavior happens. You will want this measurement so that you will be able to see the progress you and your child are making. What is the best way to record how often a problem behavior happens? It is different for different people. Some ideas include:

1. Placing post it notes throughout the home each morning and just placing a tally for each time the problem behavior happens during the day. Then record the total tallies in the morning, afternoon or evening. You could even just tally at the end of the period when the behavior is most troublesome.

2. Place a jar on the cupboard with a small bowl of marbles beside it. Each time the behavior occurs place a marble in the jar. Record how many marbles are in the jar at the end of the day or troublesome time period.

3. Use the attached pages for record keeping.

Look at the estimated totals and the measured totals, are they close?

Write the observable problem behavior, how you will measure it, and how often it can occur that you can live with it.

**Example: Tantrums look like: crying, laying on floor, pounding fist on floor and kicking**

**Observable problem behavior** ________________________________________________

**How I will measurement it?** ________________________________________________

**How often can it occur that I can live with it?** _________________________________
Reflections

How Often Does the Problem Behavior Happen in a Week?

<table>
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<tr>
<th>Daily Totals: Day</th>
<th>Total</th>
<th>Hourly Totals</th>
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</thead>
<tbody>
<tr>
<td>Sunday</td>
<td>7:00-8:00</td>
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<tr>
<td>Monday</td>
<td>8:00-9:00</td>
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<td>Tuesday</td>
<td>9:00-10:00</td>
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<td>Wednesday</td>
<td>10:00-11:00</td>
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<td>Thursday</td>
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<td>3:00-4:00</td>
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<td>4:00-5:00</td>
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</tbody>
</table>
Bar Graphing How Often the Problem Behavior Occurs in a Week

(\#) Number of times the behavior occurs in a day

<table>
<thead>
<tr>
<th></th>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
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Why Does this Behavior Happen?

Problem behavior often occurs because of one of four basic needs is not being met. These needs include: communication, acknowledgement, sensory needs, and escape (Jerome & Mukamal, 2002). In the school setting this is labeled as the “function of the behavior” or FUBA. It is important to look at why this behavior may be happening. By considering the function this behavior may serve your child, you can look at how to change the problem behavior in a more effective and positive way. You will be able to think about what your child is trying to tell you, not just at how much the behavior is bothering you or making your life or your family’s lives miserable.

Communication

Many times children that are unable to express their thoughts and desires use problem behavior as a way to communicate. This is commonly seen in young two year olds that are just learning how to talk and instead of expressing their needs through talking, they tantrum. Children with disabilities often have lower levels of speech or communication skills. They may also understand more than they can express. This may become very frustrating and the result in problem behavior.

Acknowledgement

Adults are busy people. Sometimes because adults are busy or involved in conversation with other adults, we may talk or act as if the child is not in the same room. Everyone wants to be noticed by the people that mean the most to them. Problem behavior can be a way for children to request being noticed. This becomes even more difficult if the child has a hard time communicating to include them in conversations and family interactions.

Sensory Needs

Many times children with disabilities have basic sensory needs that need to be addressed. It seems that many times their sensory development is affected by the type of disability they have. Many of the sensory needs children have as infants are intensified and
continue into older ages with children with disabilities. Problem behaviors such as biting, mouthing objects or even pinching may be the result of unmet sensory needs.

**Escape**

Children may use problem behavior to escape something they do not want to do. For an example, children may tantrum so that they do not have to finish eating if it’s something they don’t like. Problem behavior can make it possible for children to avoid something that they don’t desire or something they don’t want to do.

Think about what need your child may have that is resulting in problem behavior?

**Example:** Tantrums look like: crying, laying on floor, pounding fist on floor and kicking

**Observable problem behavior to work on first**: ________________________________

**Example:** Escape and Acknowledgement

Circle what you think is the function or reason this behavior is happening:

<table>
<thead>
<tr>
<th>Communication</th>
<th>Acknowledgement</th>
<th>Sensory Needs</th>
<th>Escape</th>
</tr>
</thead>
</table>

**Example:** When Matthew doesn’t want to ride the bus to school he tantrums, which looks like crying, laying on the floor and pounding his fist on the floor and kicking.

Write why you think this is the function or reason your child uses this behavior in detail:

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
Behavior Motivation Scale

Complete the behavior motivation scale if you are having a hard time figuring out what need your child’s problem behavior may have. Read and circle what you observe, then total at the end.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Almost Never</th>
<th>Seldom</th>
<th>Half the Time</th>
<th>Usually</th>
<th>Almost always</th>
<th>Always</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Would the behavior occur continuously, over and over if your child was left alone for long periods of time?</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior occur following a request to do a difficult task?</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior seem to occur in response to your talking to another child or adult in the room?</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior occur when your child asks for things they need or desire?</td>
</tr>
<tr>
<td>5</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Would the behavior occur repeatedly, in the same way, for long periods of time, if no one was around?</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior occur when any request is made of your child?</td>
</tr>
<tr>
<td>7</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior occur whenever you stop attending to your child?</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior occur when your child wants something that (s)he doesn’t have?</td>
</tr>
<tr>
<td>9</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does it appear to you that your child enjoys performing the behavior?</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does your child seem to do the behavior to upset or annoy you when you are trying to get him/her to do what you ask?</td>
</tr>
<tr>
<td>11</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does your child seem to do the behavior to upset or annoy you when you are not paying attention to her or him?</td>
</tr>
<tr>
<td>12</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does your child speak so that others outside the family can understand them?</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>Almost Never</td>
<td>Seldom</td>
<td>Half the Time</td>
<td>Usually</td>
<td>Almost always</td>
<td>Always</td>
<td>Behavior</td>
</tr>
<tr>
<td>---</td>
<td>-------</td>
<td>--------------</td>
<td>--------</td>
<td>--------------</td>
<td>---------</td>
<td>---------------</td>
<td>--------</td>
<td>----------</td>
</tr>
<tr>
<td>13</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>When the behavior is occurring, does your child seem calm and unaware of anything else going on around him or her?</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does the behavior stop shortly after you stop making demands of your child?</td>
</tr>
<tr>
<td>15</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does your child seem to initiate the behavior in order to get you to spend some time with her or him?</td>
</tr>
<tr>
<td>16</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>Does your child understand more than they are able to communicate?</td>
</tr>
</tbody>
</table>

Transfer the number of each question to the blanks below. The scores are organized in columns by what type of need your child may have. Add the total score and then calculate the average score of each basic need. Rank the average scores 1, 2, 3, or 4 according to each needs average score.

<table>
<thead>
<tr>
<th>Sensory</th>
<th>Escape</th>
<th>Acknowledgment</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>2.</td>
<td>3.</td>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
<td>6.</td>
<td>7.</td>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
<td>10.</td>
<td>11.</td>
<td>12.</td>
</tr>
<tr>
<td>13.</td>
<td>14.</td>
<td>15.</td>
<td>17.</td>
</tr>
</tbody>
</table>

Total Score

Avg. Score

Ranking

Adapted from Durand, V.M. (1988) in M. Hersen & A.Bellack (Eds), Dictionary of Behavioral Assessment Techniques *10/04
**Setting**

The setting is the place the challenging or problem behavior happens. The setting may include home, school, or a place in the community. Where does your child’s problem behavior you have chosen to work on happen most often? What setting is easiest for you to control? Carefully choose just one setting to begin with at a time. As your child’s behavior improves in the setting you have chosen you may be able to expand the setting to include other places.

**Example:** Tantrums look like: crying, laying on floor, pounding fist on floor and kicking

**Observable problem behavior to work on first:** __________________________________________

**Example:** in the house, in Matthew’s bedroom/ in the house, the front room by the front door/ in the house, in the kitchen by the back door

**List the places (setting) this behavior occurs:**

________________________________________

________________________________________

________________________________________

________________________________________

Choose and write the setting you are going to work on first.

**Example:** in the house, in Matthew’s bedroom

**First setting to work on where this behavior happens:**

________________________________________

________________________________________

________________________________________
Setting Events

SETTING EVENTS ARE THINGS THAT HAPPEN WITHIN A SETTING. THESE CAN INCLUDE THINGS THAT HAPPEN WHILE YOUR CHILD IS IN A CERTAIN SETTING. SETTING EVENTS CAN CAUSE THE PROBLEM BEHAVIOR TO HAPPEN MORE OFTEN OR LESS OFTEN. SETTING EVENTS ARE IMPORTANT TO CONSIDER BECAUSE MANY SETTING EVENTS CAN BE ADJUSTED TO DECREASE THE FREQUENCY OF THE PROBLEM BEHAVIOR. SETTING EVENTS CAN INCLUDE LACK OF SLEEP, MEDICATIONS, ILLNESS, AND CHANGE IN ROUTINES OR PEOPLE. WHAT SETTING EVENTS DO YOU SEE BEFORE THE PROBLEM BEHAVIOR HAPPENS WITH YOUR CHILD?

Observable problem behavior to work on first*:
____________________________________

First setting to work on where this behavior happens*:
_______________________________

Example: I (mom) yell from the kitchen for Matthew to hurry and finish getting ready to go to school. I am looking for Matthew's shoes and backpack. Matthew is still in his bedroom. I am yelling, “hurry let's go, you are going to miss the bus.”

Setting events that are present before this behavior happens: _______________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

Example: Create a morning schedule with pictures to put on the fridge. Find everything your child needs for school the night before and put by the door. Don’t yell from other room, go into the room Matthew's room and talk to him in a normal voice. Use picture schedule throughout the morning. Have Matthew put the picture of getting dressed in the basket, and take the picture of getting on the bus.

How can I manage the setting events for my child? _______________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________

__________________________________________________________________________________
**Antecedent**

The antecedent is what happens right before the problem behavior, it is what triggers the problem behavior. Think about what happens directly before the problem behavior. As a parent I call it the moment I catch my breath and hope, hope, hope that maybe this time it won’t trigger the problem behavior. Most of the time it does. Think about the behavior you have chosen to work on. What triggers this behavior? Is the problem behavior triggered by a request to do something your child doesn’t want to do, a “no”, being over stimulated by tasks or even people, or even a desire to get something or someone?

Example: Tantrums look like: crying, laying on floor, pounding fist on floor and kicking

Observable problem behavior to work on first*: ______________________________________

Example: Mom yells, “Hurry, let’s go to school. You’re late.”

What do you think happens directly before this behavior?

________________________________________________________

________________________________________________________

Often it is good to watch your child for a couple of days and record what happens right before the behavior you want to work on first and see if you are correct. I like to think about what triggers the behavior and then every time the behavior happens I just make a mental note. After taking care of my child, I write down what actually triggered the behavior.

What triggers the problem behavior?

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________

________________________________________________________
Maintaining Consequences

Maintaining consequences are what occur directly after the problem behavior. What happens after your child displays the problem behavior? What changes in their environment? How do you respond? These changes or responses to the problem behavior maybe causing the behavior to continue happening. These changes and responses can be negative or positive, it doesn’t matter. It is the maintaining consequences that make the problem behavior continue to occur.

Example: Tantrums look like: crying, laying on floor, pounding fist on floor and kicking

Observable problem behavior to work on first*: _________________________________

What do you think are the consequences that occur immediately after the behavior?

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Example: Matthew doesn’t have to ride the bus.

Mom takes him to school.        Mom yells at Matthew

Sometimes it helps to watch and record what actually happens after the problem behavior. If it is the same as you thought make a mental note. If it is different, record what occurs after you take care of your child.

After observing my child, I see that immediately after the problem the consequences are:

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Reflections
Finishing the FUBA

The FUBA (functional behavior analysis) is nearly finished. The FUBA has given you the chance to look at the problem behavior, the setting, setting events, and maintaining consequences. You have learned that problem behavior may be the result of basic needs your child may have in communication, acknowledgement, sensory needs, and the need to escape. Taking the time to work through your child's problem behavior and why it occurs. This process allows you to problem solve better. By creating a plan to help guide how you respond and help your child change their problem behavior. To finish the FUBA, fill in the pieces on the following table. This table will create a way to quickly look at the work you have completed so that next we can develop a behavior plan.

<table>
<thead>
<tr>
<th>Setting Events</th>
<th>Antecedent Behavior</th>
<th>Problem Behavior</th>
<th>Maintaining Consequences</th>
<th>Function of Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Child's bedroom with video games and toys</td>
<td>Mom in kitchen yells, &quot;Please get dressed for school.&quot;</td>
<td>Tantrum look like: crying, laying on floor, pounding fist on floor and kicking</td>
<td>Mom yells Child misses bus Mom takes to school</td>
<td>Escape (riding school bus) Acknowledgement</td>
</tr>
</tbody>
</table>

Parent:
Alternative Competing Behavior

To change a problem behavior, a new more acceptable behavior needs to be taught. Alternative competing behavior is the new behavior that will be used to replace the problem behavior. Alternative competing behaviors include behaviors that cannot physically occur at the same time your child is displaying the problem behavior. Successful alternative competing behaviors most often fulfill the same need that the problem behavior fulfilled: to communicate, to provide acknowledgement, to satisfy sensory needs, or to escape something that is hard or unpleasant.

Sometimes thinking of appropriate alternative competing behaviors takes time, creativity, and practice. This becomes easier with experience.

Complete Table:

<table>
<thead>
<tr>
<th>Problem Behavior</th>
<th>Function of the Problem Behavior: Communication, Acknowledgement, Sensory Needs, Escape</th>
<th>Possible Alternative Competing Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Positive Reinforcement**

Positive reinforcement given directly after the new alternative competing behavior increases the chances that the new alternative competing behavior will happen again. Positive reinforcement needs to happen immediately after the new alternative competing behavior. Positive reinforcement is different from person to person and time to time. Positive reinforcement may include food, objects, and eventually praise alone. Praise is powerful and should be part of whatever positive reinforcement you choose. Also, the positive reinforcement you choose to use for the new alternative competing behavior will work best if that is if the only time your child receives that reinforcement is. Positive reinforcement is not a bribe. It is important that the positive reinforcement for the new alternative competing behavior is stronger than the negative reinforcement of the problem behavior. The table below provides some ideas of possible positive reinforcement.

<table>
<thead>
<tr>
<th>FOOD</th>
<th>ACTIVITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>USE SMALL AMOUNTS (1) FOR</td>
<td>IT IS GOOD TO USE A TIMER SO THAT WHEN THE TIMER GOES OFF YOUR CHILD KNOWS</td>
</tr>
<tr>
<td>EACH TIME YOUR CHILD USES</td>
<td>THAT THE ACTIVITY IS FINISHED.</td>
</tr>
<tr>
<td>THE NEW ALTERNATIVE</td>
<td></td>
</tr>
<tr>
<td>BEHAVIOR</td>
<td></td>
</tr>
<tr>
<td>Cheetos</td>
<td>Blow bubbles</td>
</tr>
<tr>
<td>Teddy Grahams</td>
<td>Play with toy from positive reinforcement toy box</td>
</tr>
<tr>
<td>Raisons (Other dried fruit)</td>
<td>Activate simple action toy</td>
</tr>
<tr>
<td>Popcorn</td>
<td>Choose a baseball, football, or basketball card from a hat (only need to</td>
</tr>
<tr>
<td></td>
<td>use one at a time)</td>
</tr>
<tr>
<td>Dry Cereal (Remember to</td>
<td>Shoot a basket (basketball)</td>
</tr>
<tr>
<td>not use the same cereal you</td>
<td></td>
</tr>
<tr>
<td>child eats every day)</td>
<td></td>
</tr>
<tr>
<td>Dry Cereal</td>
<td>Play dress up for 3 minutes</td>
</tr>
<tr>
<td>Marshmallows</td>
<td></td>
</tr>
<tr>
<td>Mini M&amp;M’s</td>
<td>Watch favorite video for 3 minutes</td>
</tr>
<tr>
<td>Other</td>
<td>Other</td>
</tr>
</tbody>
</table>
CHOOSE ONE OR TWO WAYS TO POSITIVELY REINFORCEMENT THE NEW ALTERNATIVE COMPETING BEHAVIOR. WRITE THE POSITIVE REINFORCEMENT YOU ARE GOING TO USE. ______________________________________________________________________

EXAMPLE: MATTHEW WILL GET TO ACTIVATE A SMALL TOY CAR FROM THE POSITIVE REINFORCEMENT TREASURE BOX

Complete table:

<table>
<thead>
<tr>
<th>Problem Behavior</th>
<th>Function of the Problem Behavior: Communication, Acknowledgement, Sensory Needs, Escape</th>
<th>Alternative Competing Behavior</th>
<th>Positive Reinforcement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Consequences

It is often easier to think of negative reinforcement or consequences for the problem behavior. Many times parents use the same negative reinforcement or consequences their parents used with them. However, when working with children with disabilities what worked in the past may not work now. It may seem that nothing works to stop your child’s problem behavior. That is one of the reasons that positive reinforcement is so important. Positive reinforcement can be more powerful or able to change problem behavior than continuing to use negative consequences. Positive reinforcement should be given at least four times to every one negative consequence in order to maintain a positive and healthy parent child relationship.

Choose things you child loves so that it will be easier to have high rates of positive reinforcement and low rates of negative reinforcement or consequences.

Consequences are most effective if chosen before deciding on a behavior plan. Consequences should be ahead of time making it possible to calmly and fairly use them.

Consequence guidelines have been developed by state and school agencies. The Division of Services for People with Disabilities (DSPD) uses the Habilitation and Adaptive Behavior Development Guidelines, Utah State Department of Human Service. Utah school districts also have established guidelines. These guidelines provide appropriate and effective ideas for consequences. Sometimes consequences can be as simple as not giving the positive reinforcement. Choose consequences that are convenient and practical within your family.

Habilitation and Adaptive Behavior Development Guidelines. Only Level I guidelines will be used.

Example: When Matthew tantrums, an action toy car from the positive reinforcement treasure box goes in the time out basket for two minutes.

CHOOSE AND WRITE CONSEQUENCE: ________________________________
____________________________________
Complete table.

<table>
<thead>
<tr>
<th>Problem Behavior</th>
<th>Function of the Problem Behavior: Communication, Acknowledgement, Sensory Needs, Escape</th>
<th>Alternative Competing Behavior</th>
<th>Positive Reinforcement</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Writing A Behavior Plan

Using the alternative competing behavior and the positive reinforcement we can write a behavior plan. Remember, the behavior plan will emphasize *positive approaches*, creating *positive* adaptive behaviors. The behavior plans will not include corporal punishment, electric devices of other painful stimuli, nor will we withhold. Let’s quickly review the FUBA you developed.

**FUBA**

<table>
<thead>
<tr>
<th>Setting Events</th>
<th>Antecedent</th>
<th>Problem Behavior</th>
<th>Maintaining Consequences</th>
<th>Function of Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Take the information from the FUBA and add the alternative competing behavior and positive reinforcement you have chosen to complete the behavior plan.

**Behavior Plan**

<table>
<thead>
<tr>
<th>Alternative/Competing Behavior (Observable/Measurable)</th>
<th>Positive Consequences</th>
<th>Appropriate Negative Consequences (Must be in state guidelines)</th>
<th>Person teaching the plan</th>
<th>How will data be recorded?</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXAMPLE:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It is helpful to think of the behavior plan as teaching a new skill. Think of times when you have taught someone how to do something you already know how to do such as playing a game or sport. Teaching a new skill works best when you think through each of the steps needed to attain the skill and the easiest way of doing it. Behavior plans are the same. Think of the new alternative competing behavior as a new skill to teach. Is there a sequential order to
learning the skill? Is there an easy way to teach the skill? Also, think of how you are going to
give the positive reinforcement you have chosen. Remember that positive reinforcement works
best when it is given directly after the desired behavior. So make sure you are prepared with
the reinforcement each time you teach the new alternative competing behavior. Complete the
behavior plan.

Behavior Plan

<table>
<thead>
<tr>
<th>Who will teach the new alternative competing behavior?</th>
<th>Where and when will the new alternative competing behavior be taught?</th>
<th>Steps for how the new alternative completing behavior will be taught</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5.</td>
</tr>
</tbody>
</table>
Recording Alternative Competing Behavior Progress

Just as we needed to begin by looking at how often the problem behavior occurred, it is important to look at how often the new alternative competing behavior is happening and if the problem behavior has decreased. By recording this information it is easy to see if the behavior plan is working, and if adjustments need to be made. It will also encourage you to follow through with the positive reinforcement as you help to increase the new behavior.

Look at the data and ask yourself:

1. Is the problem behavior happening less often?
2. Is the alternative competing behavior increasing?
3. Is the positive reinforcement working for your child? Does the positive reinforcement you are using increase the alternative competing behavior?
4. Sometimes when learning a new behavior, your child will actually increase the problem behavior. Continue to use the positive reinforcement to increase the alternative competing behavior.
5. Is the problem behavior nearly gone and the new one increasing each day? If so, you have successfully completed your behavior plan. Congratulations!
**How Often Does the New Alternative Competing Behavior Happen?**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
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### Bar Graphing How Often the Problem Behavior Occurs in a Week

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Conclusion

You can decrease your child’s problem behavior. You can increase new, more appropriate behavior. It takes a lot of work but it is worth it. I began using PBS when Matthew was three years old. He is now eighteen. When we are shopping or out to a movie, no one realizes he has a disability because his behavior is appropriate. We still use PBS when a new problem behavior occurs. Matthew’s positive reinforcers have changed over the years, but the FUBA to writing a behavior plan using an alternative competing behavior still works. Learning to use PBS has helped reduce our family stress and has made it possible to have a more typical family life.

Good Luck! If you have questions or need extra help contact:
Appendix
Alternative Behavior Plan Format

Child:

Date of Birth:

Problem Behavior (observable and measurable, only one):

Functional Assessment Summary (summarize results of assessment data collected)

Hypothesis from Functional Behavior Assessment: (setting events, antecedent, problem behavior, maintaining consequences and function: e.g., when Sue gets less than 6 hours of sleep, and her mother reminds her to complete her chores after school, she whines and sometimes screams until her mother says she does not have to do it. The function of this behavior is to escape the work.)

Alternative Competing Behavior that needs to be taught: (observable, measurable, what you want to see instead): Instead of _______________ when (antecedents) ______________________ in order to (positive consequences) ____________________________.

Intervention Plan Procedures (who is responsible at each step, who will teach what, reinforcers with reinforcement schedule): (5)

Crisis Management Procedure (who is responsible at each step, what is the procedure when the child does the problem behavior?)

Data Recording (how you will determine if the problem behavior has decreased and the alternative competing behavior has increased?)
References


Wilder, L. K. (2002). *Mom, catch me a rainbow: Improving family life for families of children with disabilities by teaching parents to deal effectively with inappropriate behaviors* (Family Studies Grant). Provo, UT: Brigham Young University, Department of Counseling, Psychology and Special Education.