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Effects of a Parent Training Workshop on Parent Perceptions of Children with Developmental Disabilities

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Effects of a Parent Training Workshop on Parent Perceptions
of Children with Developmental Disabilities

Stephanie Call

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Effects of a Parent Training Workshop on Parent Perceptions of Children with Developmental Disabilities

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Master of Science

Children with developmental disabilities often exhibit problem behaviors, such as physical aggression, tantrums, and self-injury. These behaviors can detrimentally affect the family's lifestyle. Research has shown that such families should take an active role in developing and implementing a behavior plan. However, families need support to promote effective changes in their child's behavior. This study investigated how a positive behavior support workshop that used the Family HOPE program affected behavior problems and parent/child relationships in families with children with developmental disabilities. Parents of eight children with disabilities and challenging behaviors participated in this research. A Project Director and Principal Investigator taught the six systematic steps to changing behavior. They were assisted by graduate students who provided behavioral education to families, helped families complete a Functional Behavioral Assessment, appropriate interventions, and analyze intervention data. The Parent-Child Relationship Inventory (PCRI) and Scales of Independent Behavior-Revised (SIB-R) were given to the families to study the effects of parent trainings on parents' perceptions of limit setting, parental support, and the frequency and severity of problem behaviors. Results showed a significant difference in the pre- and post-intervention data on limit setting and parental support. There were no significant differences in the frequency and severity of problem behaviors on the SIB-R. Implications for further research are suggested concerning teaching parents Positive Behavior Support principles in a workshop setting.

Keywords: Positive behavior interventions, positive behavior support, functional assessment, parent-professional collaboration, developmental disabilities, autism

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *Effects of a Parent Training Workshop on Perceptions of Parents of Children with Developmental Disabilities*, is written in a hybrid format. The hybrid format brings together traditional thesis requirements and journal publication formats. The preliminary pages of the thesis reflect requirements for submission to the university. The thesis report is presented as a journal article and conforms to length and style requirements for submitting research reports to education journals. The literature review is included in Appendix A. Appendix B includes the quantitative instruments used for the study while Appendix C includes the qualitative measures. The consent form is located in Appendix D.

Introduction

Families who have children with severe problem behaviors may lack the knowledge necessary to effectively change behaviors to help improve their child's quality of life. Support is needed to help these families cope with the daily struggles that severe problem behaviors present, such as tantrums, self-injury, defiance, and physical aggression. An effective approach for supporting individuals with problem behaviors and their families is through the use of Positive Behavior Support (PBS) (Carr et al., 2002), which applies the science of behavior analysis to the social problems and environments that problem behaviors create (Horner, 2000).

Children with developmental disabilities often engage in challenging behaviors because of learning deficits in language, cognition, sensory perception, social behavior, and emotional intelligence. Because of these deficits, the problem behaviors often continue from childhood to adolescence and become a major concern for parents (Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002)

Problem behaviors such as physical aggression, self-injury, property destruction, and tantrums are common among children with developmental disabilities. Problem behaviors occur for a reason or a function; therefore, intervention is important to changing a behavior. Unless the function of the behavior is known, changing a problem behavior is very difficult (Horner, Carr, Strain, Todd, & Reed, 2002). Knowledge about the function of the problem behavior is important to determine how to replace a problem behavior with a more socially appropriate behavior that serves the same function (O'Neill et al., 1997).

Because problem behaviors are so detrimental and difficult to understand, they have an enormous impact on the life of the child. The child with the problem behavior may encounter fewer social interactions and little involvement in the community because of isolation from

family and peers. The problem behavior may also be embarrassing for the child so he or she no longer wants to go out in the community (Lucyshyn, Horner et al., 2002). This may cause families to be concerned about the absence of friendships for the child with the problem behavior (Turnbull & Ruef, 1996).

Problem behaviors may also affect the quality of life for the family because daily routines and activities may be disrupted. Outings in the community are shortened because of the embarrassment or the difficulties that the problem behaviors cause (Fox, Benito, & Dunlap, 2002). Due to the added stress within the family, health or psychological problems and marital distress may become evident (Lucyshyn, Kayser, Irvin, & Blumberg, 2002).

Families with a child with disabilities and difficult behaviors have many different perceptions about the problem behavior. Some families are concerned, embarrassed, or annoyed with the behavior, especially in public. Some behaviors are persistent, which causes a constant worry. For example, if the child has to use the restroom, he may loudly declare, "I have to go to the bathroom." This may cause embarrassment for the family, especially the sibling, but it may not embarrass the child. Families often feel that they are being nuisances in public. Turnbull and Ruef (1996) found that almost all the families that they studied wanted to go out in the community for enjoyment and relaxation but instead predicted it would be stressful and exhausting.

In order to adapt to their child's problem behavior, families learn to make accommodations within their lifestyle. Families may seek emotional support from family members or spiritual resources to help adapt to their child's behavior (Fox, Vaughn, Wyatte, & Dunlap, 2002). Many families learn how to change their schedule to best fit the needs of their child with a disability. Families also get together to form a team effort to help with their child or

sibling with a disability (Maul & Singer, 2009).

Even though families learn how to adapt to their child with a disability and problem behaviors, they may not have the resources to deal with the challenging behaviors. Family accommodations may need to be more extensive because the problem behavior may become more severe as the child grows older (Keogh, Garnier, Bernheimer, & Gallimore, 2000). In order for family accommodations to be more extensive, parents may need support from professionals. Families want a trusted, dependable professional to help create “a custom-designed, multicomponent, comprehensive system of supports and services” (Turnbull & Ruef, 1996, p. 260) that addresses and supports their child’s problem behavior.

Families need the knowledge and skills to understand their child’s problem behavior and why it occurs. They need the skills to create and implement a positive behavioral support plan and to teach appropriate behaviors and skills. This may help to improve the quality of life for the family and the child (Lucyshyn, Kayser, Irvin, & Blumberg, 2002). Most families want and need practical information about helping their child with a problem behavior that can be applied in real situations. For example, one parent noted, “Parents need strategies for applying information. We need real, concrete, follow-through ideas” (Turnbull & Ruef, 1996, p. 288).

Positive Behavior Support (PBS) is one method that teaches parents strategies to decrease their child’s problem behavior and improve their lifestyle. PBS is an applied science approach to develop individualized interventions for people with problem behaviors (Lucyshyn, Horner et al., 2002). It is a process that is based on the needs of the family and the family’s living environment, which coincides with family needs during difficult situations (Vaughn, Wilson, & Dunlap, 2002). Family-centered partnerships need to be developed within the PBS process to ensure that developments of comprehensive interventions are made to the unique family system

(Fox, Vaughn, et al., 2002).

One way to teach PBS strategies with family and professional partnerships is to provide training. Parent education programs have had positive effects on a variety of targeted behaviors in children because the parents take an active role in developing and implementing interventions that fit into the family's routines (Brookman-Fraze, 2004). One way to make parent training successful is to have a collaborative partnership with the families. Lucyshyn, Horner et al. (2002) defined collaborative partnerships within PBS as "a reciprocal relationship in which interventionists and family members believe in each other's ability to make important contributions to the support process...to solve problems together, and acknowledge each other's contributions" (p. 12). The goal of parent training and collaboration is to teach parents a process for solving problems that they can use in the future (Brookman-Fraze, 2004). Parent training attempts to help parents who are raising children with disabilities, but the research regarding its effectiveness is scarce. Despite several studies documenting the effectiveness of PBS within the home, little research documents the effectiveness of a PBS training with parents. Therefore, this study is conducted to document the effectiveness of a parent training on PBS with families raising children with disabilities and problem behaviors.

Statement of the Problem

Children with developmental disabilities may exhibit problem behaviors at home or at school for a variety of reasons. For example, the behavior may be related to the child's need to communicate, to receive acknowledgment or sensory stimulation, or to avoid an unpleasant task or aversive stimulus (Jerome & Mukamal, 2000). Many parents raising children with disabilities live with daily stress because of their child's problem behavior (Dyson, 1997; Olsson & Hwang, 2001). If parents do not receive information about overcoming problem behavior it can be a

powerful problem. They may need training and support from behavior analysts to help them understand their child's behavior and apply PBS principles in their homes (Albin, Dunlap, & Lucyshyn, 2002).

Several studies have been conducted showing sufficient evidence of the contribution of a short-term PBS approach on reducing problem behaviors of children and improving their quality of life (Dunlap & Fox, 1999; Moes & Frea, 2002; Vaughn, Wilson, & Dunlap, 2002). One such study conducted by Vaughn and colleagues (2002) found the PBS approach to be successful in reducing disruptive behaviors, such as running away and jumping on chairs at a fast-food restaurant. The study took place for nine sessions in less than a year (Vaughn, Wilson, & Dunlap, 2002).

Few studies exist regarding the long-term evidence of a PBS approach contributing to a lasting behavioral change for families raising children with disabilities. Lucyshyn et. al (2007) conducted a longitudinal study on the family implementation of Positive Behavior Support with a child with autism. They wanted to address a lifespan perspective on behavior change by extending repeated follow-up measurement for a period of seven years post-intervention. Lucyshyn et al. found that the child's problem behavior decreased and the changes maintained across the seven years of post-intervention measurement (Lucyshyn, et al., 2007). Another type of support is a short-term PBS workshop. Sufficient evaluation of the effectiveness of a short-term PBS workshop using a group design does not exist in the literature.

Families face serious challenges when raising a child with a disability and problem behaviors. Problem behaviors, such as physical aggression and self-injury, affect not only the child but also the family. Families learn to adapt to their child's problem behavior by making accommodations. However, the accommodations may need to be more extensive so that the

behavior change is durable over time. Families need support to promote effective and durable changes in their child's behavior and in the family's quality of life.

Statement of Purpose

The purpose of this study is to examine the effectiveness of a short-term PBS workshop on behavior problems and parent/child relationships in families with children with developmental disabilities. The Family HOPE (Happiness, Optimism, Promise, and Excellence) program includes a workshop-based parent training offered through Brigham Young University (BYU) for families who are raising children with disabilities and behavior problems. The program is designed to offer support and research-based methods of PBS for families raising children with disabilities to help minimize problem behaviors.

Research Questions

This study addressed the following research questions:

1. What are the differences in pre- and post-intervention ratings of the child's problem behavior frequency on the Scales of Behavior-Revised (SIB-R) as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?
2. What are the differences in pre- and post-intervention ratings of the child's problem behavior severity on the Scales of Behavior-Revised (SIB-R) as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?
3. What are the differences in pre- and post-intervention ratings in parental support on the Support Subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?

4. What are the differences in pre- and post-intervention ratings in limit setting on the Support Subscale of the Parent-Child Relationship Inventory (PCRI) as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?

Method

The methods of this study will be discussed in this section including participants, sampling, setting, materials, treatments, measures, procedures, social validity, limitations, research design, and data analysis. Informed consent was obtained from all participants before participation in the study. Consent letters included information on the study procedure, confidentiality, risks associated with the study, voluntary participation, and the benefits of the study.

Participants

Participants included parents who were raising children with disabilities (CWD) recruited from a school district and surrounding areas in suburban areas in a western state in the United States. A purposive sample of 14 parents from nine families were recruited for this study, nine of whom were married couples where both parents participated. However, three parents from two families completed the pre-intervention assessments, but did not complete the post-assessments, so their information was taken out of the study. All the parents were raising a child with disabilities (CWD) and one family was raising two children with disabilities.

Seven mothers and four fathers participated in all aspects of the study. The average age of mothers and fathers was 36.14 years and 39.60 years respectively. Mothers had completed 14.29 years of education, whereas fathers had completed 17.8 years. The majority (86%) of the families were two-parent families, and parents were raising an average of 2.71 children. Most (90.9%) of the families were Caucasian, and over half of the families (57%) earned over \$50,000

annually. Over 60% of the fathers worked full-time (M hours worked per week = 45); 86% of mothers worked part-time and no mothers worked full-time (M hours worked per week = 6). On average, the parents attended the workshop 87% of the time. See Table 1 for a description of the participants.

Table 1

Study Participants' Information

Family Number	Sex	Age	Family Composition	Education (years)	Family Income	Total Number of Children	Sessions Attended
1	Female	35	Two-Parent Family	14	Over 50,000	2	6
2	Female	42	Two-Parent Family	16	25,001-35,000	2	5
3	Female	42	Two-Parent Family	12+	Over 50,000	5	7
	Male	42		18+			7
4	Female	46	Two-Parent Family	16	Over 50,000	2	6
	Male	43		18			6
5	Female	24	Single-Parent Family	10	Under 7,000	2	6
6	Female	29	Two-Parent Family	16	15,000-25,000	3	6
	Male	31		18			6
7	Female	35	Two Parent Family	16	Over 50,000	3	6
	Male	34		19			6

To compare this sample with the larger population, Census statistics from the county in a

western state from which the study was conducted were obtained. Similar to our sample, in this county, 90.9% of people of the ages 25 or higher have graduated from high school, while 31.5% of people by the age of 25 or higher have received a bachelor's degree or higher. The average number of people per household is 3.59, which is more than our sample. The median household income for this geographic area in 2008 was \$59,701 (U. S. Census Bureau, 2010), which was similar to our sample.

The study participants were raising children with the following primary disability conditions: autism (n = 4), Asperger Syndrome (n = 3), learning disability (LD) (n = 1). The children in this study included seven boys and one girl. The average age of the CWD in the family was 8.13 years. Many of the participants did not know their child's IQ; however, one child had an IQ 85-100, another child had an IQ 115-130, and another child had an IQ of 136 in verbal and 79 in math. Several of the families stated that their child needed limited, or some degree of support (38%) in daily functioning, while 25% of families reported needing intermittent, or occasional support, 25% of families reported the need for both intermittent and extensive support, and 13% reported the need for extensive support. A majority of the children (63%) had a secondary disability such as anxiety, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, and Learning Disabilities. See Table 2 for a description of the CWDs.

Table 2*Study Participants' Children with Disabilities*

Gender	Age	Disability	Functioning Level	IQ	Secondary Disability
Male	9	Autism	Extensive Support	Unknown	Anxiety ADHD
Male	13	Autism	Intermittent & Extensive Support	85-100	Anxiety, ODD
Male	5	Asperger	Intermittent Support	Unknown	
Male	6	LD	Limited Support	Unknown	Mild Autism
Male	7	Autism	Extensive & Limited Support	115-130	
Male	7	High functioning Asperger	Intermittent Support	136-verbal 79-math processing	LD
Female	4	High functioning Autism	Limited Support	Unknown	
Male	14	Asperger	Limited Support	Unknown	Mood disorder, ADHD

Sampling

This study used a purposive sample, and families were recruited through invitations a school district in a western state sent home to parents of children with disabilities. Flyers were also posted around schools within the district to recruit families with children with disabilities. The Project Director personally invited some of the participants. If the participants were interested in the study, they contacted the Principal Investigator or Project Director. All participants who requested involvement in the study were accepted.

Setting

Each week the participants of the study met in a classroom at an elementary school in a local school district. Graduate students from BYU were randomly assigned to work with select parents throughout the duration of the training. I also participated in the study as a graduate student and was randomly assigned to work with a family. While the parents received training in PBS, the children with disabilities and their siblings were sent to a childcare room to play. A childcare coordinator and student volunteers from BYU assisted with the childcare. A school psychologist or a district representative from the school district was present at all of the meetings to oversee the training and childcare.

Materials

All of the participants in the study received *The Parent Handbook* as project material (King-Peery & Wilder, 2005). The handbook was written in a way to help parents easily understand basic principles of ABA and PBS, including a six-step process for changing behavior. The lessons in the handbook include choosing a problem behavior for change, measuring behavior by collecting data, determining the problem behavior's function, creating a functional behavior assessment, creating a behavior plan, teaching the new alternative behavior plan, and teaching the new alternative behavior. Each week the parents learned one lesson from the handbook and were required to complete homework assignments related to each lesson.

Treatments

This study was adapted from previous research of in-home training on parental perceptions of child behavior and well-being. It was adapted to a workshop model to offer the training to more families in a group setting. Throughout the study the Project Director and Principal Investigator taught the participants six systematic steps for changing behavior. Each

week the training was videotaped and uploaded to the Family HOPE website. If parents were unable to attend the workshop, they were encouraged to watch the video. The first week the parents learned the purpose of the Family HOPE project, which is to help support families raising children with disabilities and problem behaviors. The parents learned the definition of PBS, signed consent forms to participate in the study and to allow video to be taken during the trainings, and completed all of the pre-intervention measures. Parents filled out the *Family Information Questionnaire* and the *Child with Special Needs Description* form. Graduate students were available to help clarify questions parents had concerning the questionnaires.

The second week the parents identified three problem behaviors of their child and then chose the behavior that caused the most disruption in their family routines. The parents were encouraged to work on the problem behavior throughout the study and write it in observable and measurable terms. Next, the parents learned about measuring the behavior to see how often the behavior happens (frequency) or the amount of time the behavior occurs (duration).

The third week the parents learned about the different functions of challenging behavior, including to communicate with others, to express a desire for acknowledgement, to fulfill unmet sensory needs, or a desire to escape activities, tasks, or people (King-Peery & Wilder, 2005). In order to help them determine the function of their child's problem behavior, the parents completed a behavior motivation scale that was adapted from Hersen (1988) and Gerard (1994). Once the function of the behavior was determined, the parents were able to write a functional behavior summary statement, which explicitly described the problem behavior and the function of the behavior. The parents also learned about creating a functional behavior assessment (FBA). A FBA helps determine the setting, setting events, antecedent, problem behavior, and maintaining consequences. Each will be described.

Setting. The place where the problem behavior occurs is the setting, which may include home, school, church, or any other place in the community. The parents identified the setting in which the problem behavior occurred the most or the setting in which they wanted to problem behavior to decrease.

Setting events. Setting events increase the possibility that the target behavior will occur when in the presence of the antecedent. They may influence the problem behavior within the person's environment or daily routines (King-Peery & Wilder, 2005). Setting events may occur immediately or hours before a problem behavior occurs and can include environmental factors (e.g., unplanned schedule changes), social factors (e.g., an encounter with a mean friend), or physiological factors (e.g., medication) (Alberto & Troutman, 2006).

Antecedent. The antecedent is any condition or stimulus that takes place immediately preceding the behavior (Cooper, Heron, & Heward, 2007). The antecedent "triggers" the behavior. The parents were asked to watch their child for a week to record what happened right before the problem behavior occurred.

Problem behavior. Problem behaviors cause disruption and challenges in family routines and cause a great amount of stress. The parents were taught how to identify the problem behavior and write it in observable and measurable terms.

Maintaining consequences. Consequences occur right after the problem behavior. The consequences, both positive and negative, that happen after the problem behavior may increase the chance that the behavior will occur again. Parents were asked to observe and identify both the positive and negative consequences that occurred immediately after the problem behavior.

The fourth week the parents were taught about alternative competing behaviors. An alternative competing behavior is the new behavior that is used to replace the problem behavior

by fulfilling the same function that the problem behavior satisfied (King-Peery & Wilder, 2005). The parents were then taught about positive reinforcement, which helps to increase the chance of the alternative competing behavior occurring again if used immediately after the desired behavior. Positive reinforcement may include food, objects, activities, and praise. The parents were also taught about negative consequences in case the child performed the problem behavior instead of the alternating competing behavior. A negative consequence can be as easy as not giving the positive reinforcement or putting the positive reinforcement item in “time-out.” Parents were taught to use consequences that are kind, convenient, and appropriate.

After completing the FBA and learning about alternative competing behavior, positive reinforcement, and negative consequences, the parents were taught how to create a simple behavior intervention plan (BIP). Before the parents could implement the BIP, the Program Director and the Principal Investigator went over the plans to ensure that the plan followed PBS and ethical principles.

The fifth week parents were taught four different ways to teach the alternative competing behavior to their child with a problem behavior. The different ways of teaching the alternative competing behavior included a social story, power card, task folder, and role play.

The sixth week parents received a review of the previous training concepts. The parents reviewed their FBAs and BIPs. The parents wrote a lesson plan for the behavior intervention by using the lesson plan in the Parent Handbook.

The seventh week parents completed a handout that summarized the implementation of the behavior plan, data collection, and other simple adjustments that needed to happen. They completed the SIB-R and the PCRI. They also completed post-intervention measures. Awards were given to the parents for completing and participating in the study.

For the eighth week of the study, the parents were contacted by telephone for a follow-up on the behavior plan. The graduate students made sure that the behavior plan was being implemented and asked if the parents had any questions or concerns.

Participants who did not finish the duration of the program were in no way penalized. However, those who did complete the entire program and submitted all data forms were provided gift certificates.

Measures

Several measures were completed by the parents, either on their own or with the help of a graduate student, before and after the intervention. Each measure will be described.

Parent-Child Relationship Inventory. The purpose of the *Parent-Child Relationship Inventory* (PCRI) is to assess parent attitudes towards their children and the task of parenting. The PCRI gives an overall view of the parent-child relationship and it identifies problematic relationships. It is an inventory for parents raising children between the ages of 3 and 15. The PCRI is standardized based on more than 1,100 parents from the United States. The internal consistency of the test was found to be good ($r = .82$) and the test re-test reliability indicated good stability. The social desirability indicator and the inconsistency indicator are two validity indicators that are embedded in the PCRI to detect socially acceptable answers and to find parents' inclination toward inconsistent responses (Gerard, 1994).

The PCRI is comprised of eight sections, including Parental Support, Satisfaction with Parenting, Involvement, Communication, Limit Setting, Autonomy, Role Orientation, and Social Desirability. The statements within the eight sections are rated, added, and converted into t-scores to compare individual scores to the norming sample. A Likert scale (4 = strongly agree to 1 = strongly disagree) is used for the responses on the inventory (Gerard, 1994). Test-retest

reliability has been reported to be 0.68 to 0.93 after one week and 0.44 to 0.79 after five months (Rohrbaugh, 2008).

The sections of the PCRI used in this study were Limit Setting and Parental Support because of their relevance to parents raising children with disabilities. The Limit Setting scale measures the effectiveness of the parent's discipline techniques. A high score on this scale suggests a controlled and pleasant situation in the home (Gerard, 1994). The Limit Setting scale includes 12 statements. An example statement is, "I have trouble disciplining my child.

The Parental Support scale measures a parent's recognition of emotional and practical support. A lower score indicates that a parent feels parenting is a burden and has a very stressful life (Gerard, 1994). Sample questions from the Parental Support scale include; "When it comes to raising my child, I feel alone most of the time.", "I get a great deal of enjoyment from all aspects of my life.", "I sometimes feel if I don't have more time away from my child I'll go crazy."

Scales of Independent Behavior-Revised. The purpose of the *Scales of Independent Behavior-Revised* (SIB-R) is to provide a comprehensive, norm-referenced assessment of adaptive behavior and problem behavior to determine a person's level of functioning. This study focused on the problem behavior, so the Maladaptive Behavior section was the only section used. This section provides a maladaptive behavior score which considers the following categories of behavior: 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. The frequency and severity of the behavior is rated on a Likert scale. Frequency ratings include 0 = never, 1 = less than once a month; 2 = 1 to 3 times a month; 3 = 1 to 6 times a week; 4 = 1 to 10 times a day; and 5 = 1 or more times an hour. Severity

ratings include 0 = not serious; not a problem; 1 = slightly serious; a mild problem; 2 = moderately serious; a moderate problem; 3 = very serious; a severe problem; and 4 = extremely serious; a critical problem. The Maladaptive Behavior Indexes range between .83 and .88 for test-retest reliability (Bruininks, Woodcock, Weatherman, & Hill, 1996).

Child with Special Needs Description. A *Child with Special Needs Description* (CWSND) questionnaire was given to all of the parents in the study to gain information in the following areas: adaptive skills/levels of support the child needed, classification and intellectual functioning, physical health, mental health, etiology considerations, and the environmental and cultural contexts the child engages in. This questionnaire was developed based upon information from the American Association on Mental Retardation (1992).

The Adaptive Skills/Levels of Supports section rated the child's need for support in the following areas: 1 = intermittent, 2 = limited, 3 = extensive, and 4 = pervasive. Intermittent support means that support is provided temporarily, infrequently, or only for the short term. Limited support means that support is provided on a regular basis for a short period of time. Extensive support means that support is needed regularly in several settings and may last for long periods of time. Pervasive support means that support is constant and intense in all settings. The Adaptive Skills/Levels of Supports included 11 statements that were rated as intermittent, limited, extensive, or pervasive. The 11 statements included the following areas: communication, self-care, home living, social skills, community living, self-direction, health and safety, academics, leisure, work, and mobility.

The Classification and Intellectual Functioning section of the CWSND included the primary diagnosis of the child, the education classification listed on the child's Individualized Education Program (IEP), and the child's approximate IQ level (if known).

The Physical Health, Mental Health, and Etiology Considerations section included any physical health related conditions the child may have. It also included any psychological difficulties the child may experience and the cause (if known) of the child's condition.

Family Information Questionnaire. The purpose of the *Family Information Questionnaire* was to gain information on the demographics of each family. It included questions about the family's ethnicity, age, income, religious preference, occupation of parents, and years of education completed.

Parent Survey. The Parent Survey was developed by the Project Director and has been used for approximately 10 years in association with parent-training as a measure of social validity. During this study, it was given to each family at the end of the study for feedback regarding the training in functional behavior analysis and developing behavior plans, and working with their graduate students. Parents completed the survey anonymously and mailed it to the Principal Investigator. One Parent Survey was submitted by each family that completed the training, with the exception that both parents from one family each submitted the survey. The survey includes the following open-ended questions:

- What was the most important thing you learned about changing problem behaviors?
- How did your assigned students help you the most?
- Was *The Parent Handbook* clear and easy to follow? Why or why not?
- Were you able to change your child's problem behavior? Why or why not?
- What would you recommend to do differently to help families in the future who participate in this research project?

Procedures

The BYU Institutional Review Board approved this study for human subjects before

implementation. Parents signed a consent form to be a research subject before they participated. The consent form included information on the study procedure, confidentiality, the risks associated with the study, voluntary participation, and the benefits of the study.

The experimental design for this study was a pre-test, post-test experimental design. This design was appropriate because it allowed for the effective measurement and comparison of differences in pre and post-ratings. The pre- and post-tests served as the independent variable, while the behavior problems and parent/child relationships in families with children with developmental disabilities served as the dependent variable.

Research Design

For this study, a one group pre- and post-test design was implemented, and a Wilcoxon test was used to compare the pre- and post-scores of parents' perceptions of (a) the frequency of their child's problem behavior; (b) the severity of their child's problem behavior; (c) the parental support received; and (d) their parental limit setting skills. This design allowed for the effective measurement and comparison of differences in pre- and post-ratings of the Problem Behavior, Limit Setting, and Parental Support subscales.

Data Analysis

Pre- and post-intervention data on the PCRI and SIB-R were gathered on each family approximately eight weeks apart. Parents were given the instruments at the beginning of the study and after the intervention was completed. A mean score of the pre- and post- intervention administrations from both parents were calculated from the Limit Setting and Parental Support subscales within the PCRI.

Data from the SIB-R were analyzed using change scores on the frequency (0–5) and severity (0–4) of the specific problem behavior. The parents chose the specific problem behavior

category (i.e., 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) that represented their child's most problematic behavior. For example, for a family working on decreasing their child's disruptive behavior, frequency and severity scores would be taken from the "Disruptive Behavior" section of the maladaptive behavior portion of the SIB-R. Frequency and severity scores for each problem behavior category were added and the problem category with the highest numerical value was used for analysis. If categories had the same highest numerical value, the parents chose the category that they thought was most problematic.

Pre- and post-intervention ratings of the SIB-R were analyzed using a non-parametric Wilcoxon test to determine the differences in the behavior's frequency and severity. Scores were analyzed from only the target category that was used in the behavior support plans, not the average SIB-R scores. On the PCRI, the pre- and post-intervention mean scores of the Limit Setting and Parental Support ratings were analyzed using a Wilcoxon test. Results were defined as significant with a p value of $<.05$.

Results

This section includes the results obtained from the statistical analysis. The total number of participants recruited for this study was 14. However, during pre- and post-testing not all protocols were completed accurately by the parents or returned to the researchers. Three participants from the study, one couple and one father, did not complete or return all assessments, so their data were removed from statistical analysis. The Wilcoxon test was conducted to compare the pre- and post-test scores because of the small sample size (Pallant, 2007). The underlying data was ordinal; therefore, the proper estimate of central tendency is the

median and the proper inference test is the Wilcoxon. The Wilcoxon focused on whether the median of the variables differs significantly.

Problem Behaviors

Frequency. The first research question examined whether there was a difference from pre- to post-test in the frequency of the child's problem behavior on the SIB-R, as rated by mothers and fathers who participated in an eight-week PBS parent workshop. A Wilcoxon test examined the results of the pre-test score and the post-test score of the frequency of the behaviors on the SIB-R. No significant difference was found ($Z = -1.65, p > .05$). Median post-test scores ($Md = 22.00$) were not significantly different from median pre-test scores ($Md = 22.00$).

During the eight-week study, parents were asked to record pre-intervention data for one week and post-intervention data for one week on their child's problem behavior. See Table 3 for the results. According to data recorded by the parents, the targeted problem behavior decreased after the PBS training. The function of the behavior shows the reason the behavior occurred. The outlying data may be a result of one participant having a learning disability, which may have impeded her understanding of how to accurately collect the data on the child's behavior (see Table 3 and Figure 1).

Severity. The second research question investigated whether there was a difference in the severity of the child's behavior on the SIB-R as rated by mothers and fathers who participated in the eight-week PBS parent workshop. A Wilcoxon test examined the results of the pre-test score and the post-test score of the severity of the behaviors on the SIB-R. No significant difference was found in the results ($Z = -2.15, p > .05$). Median post-test scores ($Md = 12.50$) were not significantly different from median pre-test scores ($Md = 13.50$).

Parental Support

The third research question assessed the differences in the pre- and post-intervention ratings on the Parental Support subscale of the PCRI as rated by mothers and fathers who participated in the eight-week PBS parent workshop. The positively stated questions on the PCRI were reverse coded before analysis. A Wilcoxon test was also used to examine the results of the pre-test and post-test scores on the parental support scale. A significant difference was found in the results ($Z = -2.33, p < .05$). Median post-test scores ($Md = 21.00$) were significantly different from the median pre-test scores ($Md = 18.00$), indicating parents felt they had better parental support after the study was conducted.

According to the Parent Survey qualitative data, every family expressed their gratitude for the help from their graduate student. Graduate students provided support and understanding for the parents. One parent wrote that their graduate student “helped think through the problems and helped me to understand how to apply the lessons to practical applications.” Even though parents did not see a significant change in their child’s problem behavior, they observed a change in their own behavior. From the Parent Survey, 75% of the parents stated that learning about the behavior plan was the most important thing learned, while 15% said learning about being positive was the most important. According to the Parent Survey, 88% of the parents thought the handbook was very clear, while the parent with a disability expressed difficulties understanding the handbook. Every family stated that their child’s behavior changed throughout the training. Two parents stated the need for more case study examples throughout the workshop. One parent wrote, “Having what other parents’ solutions to problems are actually helpful to dealing with your own!”

Limit Setting

The fourth research question asked if there was a difference in pre- and post-intervention ratings on the Limit Setting section of the PCRI as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop. A Wilcoxon test assessed differences in the pre-test and post-test scores on limit setting. A significant difference was found in the results ($Z = -2.814$, $p < .05$). Median post-test scores ($Md = 31.50$) were significantly different from the median pre-test scores ($Md = 27.50$), signifying parents felt they had better limit setting skills after the study was conducted.

Table 3

Study Participants' Pre- and Post-Intervention Frequency and Duration Data

Family	Behavior	Function	Pre (Frequency)	Post (Frequency)	Pre (Duration)	Post (Duration)
1	Tantrums	Acknowledgement	6	2		
2	Tantrums	Acknowledgement			145 min in week	60 min in week
3	Non-compliant	Avoidance	24	2		
3	Tantrums, Complaining	Avoidance	6	2		
4	Tantrums	Avoidance, Acknowledgement	13	3		
5	Non-compliance	Escape	306	237		
6	Tantrums	Escape	51	29		
7	Non-compliance	Acknowledgement	23	2		

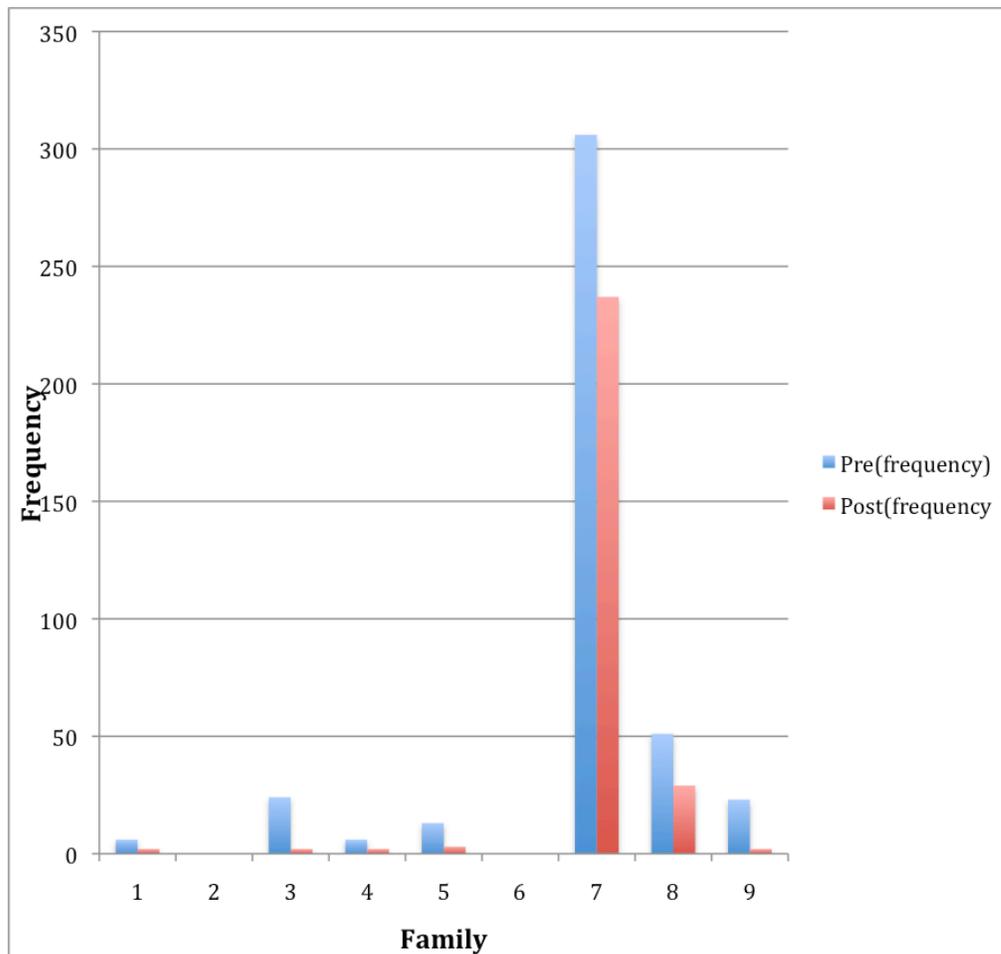


Figure 1. Pre- and post- frequency data on problem behaviors from parent data.

Discussion

The purpose of this study was to investigate the effects of an eight-week parental training workshop on Positive Behavior Support to parents raising a child or children with disabilities and problem behaviors. The study examined whether the training was able to (a) reduce the frequency of problem behaviors displayed by their child; (b) reduce the severity of their child's problem behavior; (c) help parents improve their parental support skills; and (d) help parents improve their limit setting skills. Results indicate that there was not a significant difference in the frequency and severity of problem behaviors, which suggests that our hypothesis that the training would help decrease their child's problem behavior is not supported. However, results showed a

significant difference in parents' limit setting skills and feelings of parental support.

Discussions of these findings are included in the following paragraphs.

What are the differences in pre- and post-intervention ratings of the child's problem behavior frequency as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop? A significant difference was not found in the frequency of problem behavior over time for participating families. This may be attributed to a lack of a sensitivity of the measuring instrument. The SIB-R's frequency scale in the maladaptive section does not have a consistent time interval. For example, one interval is one to 3 times a month while the next interval is one to 6 times a week. This may make it difficult for parents to record changes in their child's behavior because there are wide gaps of time between each interval. However, during the study, the parents implemented a behavior plan created with the help of the Principal Investigator, Project Director, and the graduate students in which they assessed the behavior of their child with a disability. The raw data showed that the behaviors decreased after the professional help of the parent training. A characteristic of PBS is an emphasis on parent-professional collaboration, which may have contributed to parents' report of a reduction in the problem behaviors.

What are the differences in pre- and post-intervention ratings of the child's problem behavior severity as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop? Parents rated the change in severity of problem behaviors as insignificant. The SIB-R may not have been sensitive to detecting the severity of problem behavior change after only eight weeks because the Likert scale used to assess the severity may have been too broad and it is not very definitive. For example, one response states slightly serious, a mild problem while the next response says moderately serious, a moderate problem. Parents' ratings

on the SIB-R may not detect subtle changes in behavior, such as how the behaviors are detected with the raw data because the SIB-R lacks sensitivity to detect the slight changes. Maladaptive behaviors, such as those recorded in the SIB-R are difficult to quantify because their occurrence may vary more from day-to-day and from setting-to-setting. Increasing the length of the study may have helped to strengthen the significance of the data by giving families more time to assess a behavior change. Research has shown that studies conducted with teaching families to implement a positive behavior support plan for more than eight sessions have a significant decrease in the severity of the problem behavior (Buschbacher et al., 2004; Lucyshyn et al. 2007; Vaughn et al., 2002).

What are the differences in pre- and post-intervention ratings in parental support as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?

The PCRI was used to investigate parent perceptions to determine if parents felt a greater sense of parental support. Throughout the study, the parents may have felt more support because of the workshop framework. Some research indicates that parents cope with the difficult family challenges of raising a child with a disability and problem behaviors by having good communication with other parents (Maul & Singer, 2009). Because several families attended the training, they were able to learn from each other and support each other in the learning process. These parents may have been able to learn that other parents experience similar problems with raising a child with a disability.

Also, parents were appreciative for the PBS education from the professionals because they were able to gain support in understanding their child's problem behavior and structuring home routines. Past research indicates that families want individuals to provide support and provide assistance when working with their child with a disability and his or her problem

behavior (Fox et al. 2002; Lucyshyn, Horner et al., 2002; Turnbull & Ruef, 1996). Some research indicates that parent-professional collaboration is effective in enhancing the quality of life for families raising children with disabilities because they obtain the skills necessary for implementing positive behavior plans (Brookman-Frazee, 2004).

What are the differences in pre- and post-intervention ratings in limit setting as rated by mothers and fathers who participated in eight weeks of a PBS parent workshop?

Research shows that families feel concerned when raising a child with a disability and problem behavior because they often do not have the strategies to discipline their child. Their child may not understand the family rules and social expectations, so the parents felt distressed about having a different set of consequences for their child (Fox et al., 2002). The increase in the parents' assessments of their limit setting skills may be due to the lack of stress in the home from the reduction of problem behaviors. Brookman-Frazee also found that when parents collaborate with professionals in creating behavior plans, parents demonstrate lower stress levels and higher confidence in parenting (2004).

During the training, parents were able to change their own perception of their skills as parents, which may have helped decrease the problem behavior. Several parents in the current study stated that the most important thing that they learned during the workshop about changing problem behaviors during the workshop was focusing on the positive behaviors that their child displayed. One family said that the most important thing that they learned from the study about teaching their child appropriate behaviors was, "To focus on everything our son does that is positive and tell him and reward him constantly."

Limitations

Although this study showed significant changes in parent perceptions regarding their

ability to set limits for their children with disabilities and their feelings of support, there are limitations to the external validity.

First, the sampling procedure was limited because this study included participants from a convenience sample of parents raising children with disabilities in a district and surrounding area in one western state. Because selection was not randomized the sample may not be a good representation of the population. Also, the participants who volunteered to participate in the study may have been more willing to learn and change the behavior of their child with a disability than families who did not participate. All participants wanting to participate in the study were selected.

Second, the study only occurred over an eight-week period, limiting the possibility of substantial and sustained behavior change. Also, the measures, such as the SIB-R, that were used to study the research questions, may not have been sensitive enough to detect changes in problem behaviors within a short period of time.

A critical component to a successful intervention is the involvement of family members in the process of assessment and implementation of the behavior plan (Vaughn et al., 2002). Although most of the participating families had either the mother or father in attendance every week, in some cases, the parents were unable to attend the PBS workshop. This was a limitation to external validity because both spouses were not taught the fundamentals of PBS and creating a behavior plan, which may have inhibited the creation and implementation of the plan with the child.

Third, the testing protocols completed by the parents were not controlled for screening out responses due to social desirability. The parents could have over reported good behavior and underreported bad behavior. Likewise, the lack of fidelity of a behavior plan was also a

limitation for this study. Graduate students helped the families create a behavior plan; however, the graduate students did not go into the families' homes to check whether or not the families were implementing their behavior plan correctly and collecting accurate data on the challenging behaviors.

Finally, the experimental design was limited because there was no control group with which to compare results. This limits the power of the results of this study.

Implications for Future Research

Future research is encouraged with larger samples sizes and a longer duration of workshop training. This study could also be strengthened by having a graduate student go into the parents' homes several times to determine whether the family is implementing their behavior plan. Following up with the families for maintenance after the training was completed could strengthen this research. Future research should include interobserver agreement by having another observer, such as a classroom teacher, measure the child's problem behavior. Also, including more in depth training on data collection, such as having the parents practice collecting data by watching a video, may have helped provide more reliability with the data. Few studies exist on the long-term evidence of a PBS approach for parents in a group design; therefore, extended research is recommended with teaching parents PBS through a workshop model.

Implications for Practitioners

Parents raising children with disabilities face difficulties when trying to understand their child's problem behaviors so it is important for professionals to understand parent perspectives and involve them in parent trainings to help them improve their quality of life. When designing behavior support plans, professionals should take the family perspectives and family systems into consideration because the parents know the strengths, weaknesses, needs and preferences of

their child (Buschbacher et al., 2004; Lucyshyn, Dunlap, & Albin, 2002). The support from professionals should reduce problem behaviors exhibited from the child, which, in turn, will help improve his or her quality of life as well as the quality of life for the parents and other family members (Horner, 2000). Understanding the family structure and how families respond to and cope with having a child with a disability and problem behaviors is important to understand because it will affect how parents interact with their child.

Conclusions

This study illustrated the use of the Family HOPE workshop to teach parents PBS concepts to help decrease their child's problem behavior and to improve the family's quality of life. Over the course of an eight-week workshop, parents learned Positive Behavior Support strategies to help them focus on their abilities to reduce problem behaviors of their child, to set limits, and to increase support to the family. Results indicated that parents felt more confident in their abilities to set limits and felt that they had received parental support. However, problem behaviors did not show a significant decrease. Future research is needed on the effects of a PBS workshop with families raising children with developmental disabilities.

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Table 2*Study Participants' Information*

Family Number	Sex	Age	Family Composition	Education (years)	Family Income	Total Number of Children
1	Female	35	Two-Parent Family	14	Over 50,000	2
2	Female	42	Two-Parent Family	16	25,001-35,000	2
3	Female	42	Two-Parent Family	12+	Over 50,000	5
	Male	42		18+		
4	Female	46	Two-Parent Family	16	Over 50,000	2
	Male	43		18		
5	Female	24	Single-Parent Family	10	Under 7,000	2
6	Female	29	Two-Parent Family	16	15,000-25,000	3
	Male	31		18		
7	Female	35	Two Parent Family	16	Over 50,000	3
	Male	34		19		

Table 3*Study Participants' Children with Disabilities*

Gender	Age	Disability	Functioning Level	IQ	Secondary Disability
Male	9	Autism	Extensive Support	Unknown	Anxiety ADHD
Male	13	Autism	Intermittent & Extensive Support	85-100	Anxiety, ODD
Male	5	Asperger	Intermittent Support	Unknown	
Male	6	LD	Limited Support	Unknown	Mild Autism
Male	7	Autism	Extensive & Limited Support	115-130	
Male	7	High functioning Asperger	Intermittent Support	136-verbal 79-math processing	LD
Female	4	High functioning Autism	Limited Support	Unknown	
Male	14	Asperger	Limited Support	Unknown	Mood disorder, ADHD

Table 4

Study Participants' Pre- and Post-Intervention Frequency and Duration Data

Family	Behavior	Function	Pre (Frequency)	Post (Frequency)	Pre (Duration)	Post (Duration)
1	Tantrums	Acknowledgement	6	2		
2	Tantrums	Acknowledgement			145 min in week	60 min in week
3	Non-compliant	Avoidance	24	2		
3	Tantrums, Complaining	Avoidance	6	2		
4	Tantrums	Avoidance, Acknowledgement	13	3		
5	Non-compliance	Escape	306	237		
6	Tantrums	Escape	51	29		
7	Non-compliance	Acknowledgement	23	2		

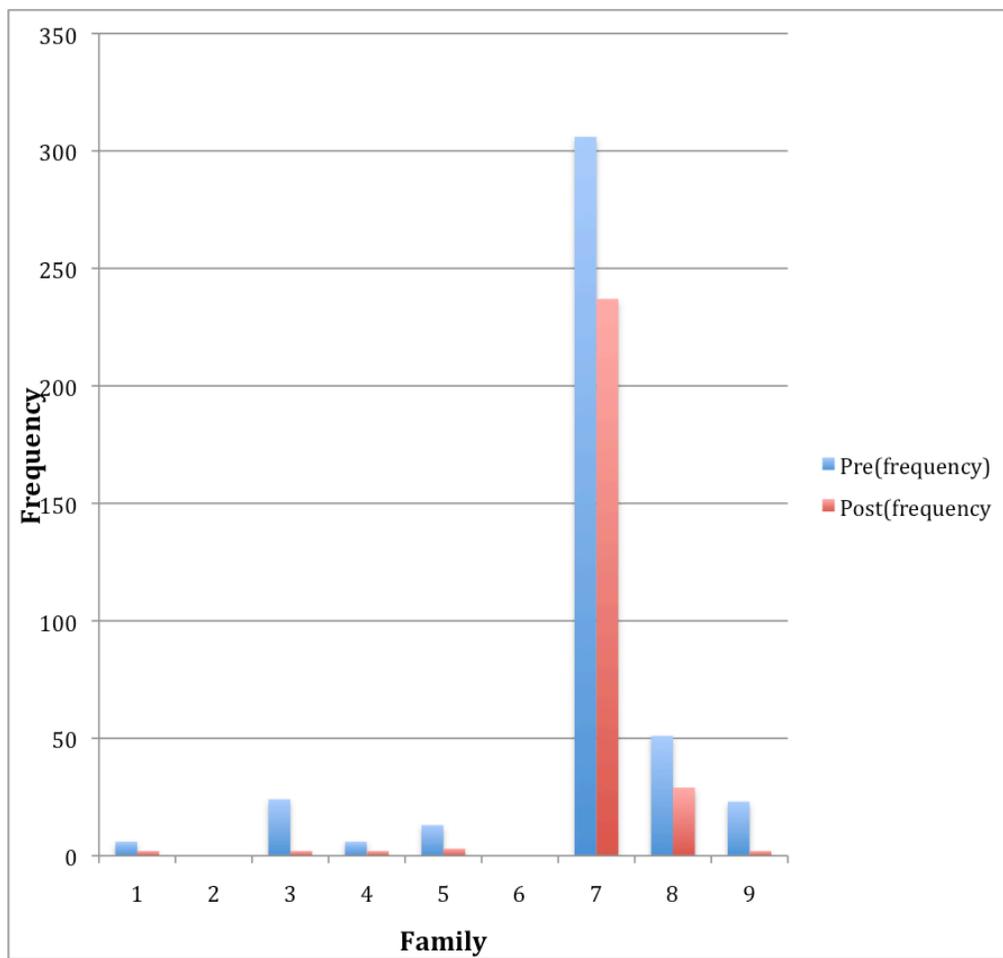


Figure 2. Pre- and post- frequency data on problem behaviors from parent data.

APPENDIX A

Review of Literature

This section reviews the existing literature regarding (a) the nature of developmental disabilities, (b) the challenges of parents who are raising children with disabilities, (c) interventions to address challenging behaviors, and (4) efforts to train parents to use Positive Behavior Support strategies to reduce challenging behaviors.

Developmental Disabilities

According to the Developmental Disabilities Act, section 102(8), developmental disability is “a severe, chronic disability, attributable to a mental or physical impairment or a combination of mental and physical impairments.” Substantial functional limitations occur in three or more of the following areas of major life activity: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, and (g) economic self-sufficiency (University of Minnesota, 2010). Developmental disabilities may include disabilities such as pervasive developmental disorders, intellectual disability, Down Syndrome, cerebral palsy, and brain injury (University of Minnesota, 2010). This review will present information regarding pervasive developmental disorders, as most research participants were raising children with these disorders.

Pervasive Developmental Disorders. Pervasive Developmental Disorders (PDD) describe a group of five developmental neurological disorders including Autistic Disorder, Asperger Disorder, Rett Syndrome, Childhood Disintegrative Disorder (CDD), and PDD – Not Otherwise Specified (American Psychiatric Association, 2000). PDD is an umbrella term for autism spectrum disorders (ASD) (American Psychiatric Association, 2000). The two most common ASDs are autistic disorder and Asperger disorder. Each will be described.

Autistic disorder. According to the Individuals with Disabilities Education Improvement Act (IDEA) (2004), “Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a student’s educational performance” (Sec. 300.8). Autism is typically identified during the second year of life because of the child’s lack of language and social interactions. Over the last 40 years, the prevalence of autism has increased dramatically, but there is no known cause for autism.

In individuals with autism, social abilities such as forming relationships, imitating another person, sharing a focus of attention with another person, and understanding another person’s emotions are typically impaired. Individuals with autism also have deficits with their ability to express their emotions (Mash & Barkley, 2003).

Another common characteristic of autism is having a limited understanding and use of language (Fox, Benito, & Dunlap, 2002). Individuals with autism have a significant delay in verbal and nonverbal language. For individuals who are able to speak, their language is characterized by immediate or delayed echolalia, abnormal prosody, and pronoun reversal. Language delays become more obvious during social interactions. For example, individuals with autism may communicate irrelevant detail in conversations (Mash & Barkley, 2003).

Additional common characteristics of autism are repetitive behaviors and interests (Leblanc, Richardson, & McIntosh, 2005). Children with autism often engage in repetitive motor movements such as rocking, toe walking, arm, hand, or finger flapping, and whirling. These types of behaviors usually occur in younger, lower functioning children with autism. Individuals with high-functioning autism often engage in more elaborate routines including rearranging or ordering of toys, insistence on following the same sequence of events during everyday activities,

and memorization of facts (Mash & Barkley, 2003).

Asperger Disorder. The DSM-IV diagnostic criteria define Asperger disorder as having a severe impairment in social interaction with restricted, repetitive behaviors and interests.

Researchers have agreed that individuals with Asperger disorder have intact intellectual and language functioning, but impairments in reciprocal social interaction (Mash & Barkley, 2003).

The DSM-IV states that individuals with Asperger disorder do not display delays in language, cognitive function, or adaptive behavior.

One primary difference between Asperger disorder and autistic disorder is language and communication. Children with Asperger disorder develop communication skills within the typical range for the first few years of life. They tend to have literal speech with concrete images and poor abstraction. They may talk in a monotonous speech patterns and talk for extended periods of time about their specific interests, even though the listener may not be listening. Social isolation occurs because of their inappropriate social communication (Neihart, 2000).

Young children with Asperger disorder often experience behavioral and emotional problems because of their lack of social knowledge (Fox, Benito, & Dunlap, 2002). They demonstrate significant difficulty making and keeping friends because they lack the social skills to initiate or engage in age-appropriate conversation. They may show little or no interest in spontaneous sharing of enjoyment, activities, or accomplishments and typically do not show empathy for someone in need (Amend, Schuler, Beaver-Gaving, Beights, 2009).

Individuals with Asperger disorder usually need to have a continual routine because they actively or aggressively resist change. Like autism, individuals with Asperger Syndrome may have stereotypical behaviors such as hand or finger flapping. They may also have conduct problems, aggression, and hyperactivity (Barnhill, Hagiwara, Myles, Simpson, Brick, &

Griswold, 2000).

Children with ASD are often at risk for problem behaviors such as tantrums, self-injury, sleep disturbances, eating disturbances, abnormal fears and response to sensory stimuli, resistance to change in daily routines, defiance, stereotypes, and physical aggression, which can negatively affect their education, social relationships, and family life (Matson & Nebel-Schwalm, 2005; Mash & Barkley, 2003). Problem behaviors put the child and others around them at risk, which limits their community and educational activities (Matson & Nebel-Schwalm, 2005).

Children with disabilities and problem behaviors simply do not “outgrow” their behaviors. If the problem behaviors are not addressed while the child is young, there is an expectation that the behavior will maintain or worsen. Research shows that early intervention that includes functional behavioral assessment has a positive effect on problem behaviors (Horner, Carr, Strain, Todd, & Reed, 2002). Early intervention is vital to the achievement of long-term and meaningful outcomes (Dawson & Osterling, 1997).

Fox, Benito, and Dunlap (2002) studied the effects of early intervention with an Individualized Support Plan (ISP) for Joseph, a 2-year-old boy with autism who had prolonged tantrums throughout the day. The ISP centered on the Positive Behavior Support framework for understanding the family’s needs and developing interventions for positive outcomes. Throughout the study, the family’s feelings of despair diminished because Joseph’s problem behavior was reducing. The family became more aware of the events that were triggering Joseph’s problem behavior and they were able to develop strategies that were appropriate for Joseph. The early intervention with ISP helped the family enjoy being in the community. With the guidance from the ISP, Joseph was able to transition to kindergarten.

Challenges of Parents Raising Children with Developmental Disabilities

When a child is diagnosed with a disability, families may struggle emotionally. Parents of children with disabilities face more challenges and have higher stress levels than parents who do not have children with disabilities (Dyson, 1997). It is assumed that the extra stress of caring for a child with a disability can lead to parental depression (Olsson & Hwang, 2001). Children with disabilities and problem behaviors cause a great amount of stress in the family because the family may experience physical exhaustion, social isolation, and marital distress (Lucyshyn, Kayser, Irvin, & Blumberg, 2002). Fox, Vaughn, Wyatte, and Dunlap (2002) found that problem behavior affected the emotional stability of the family because it was so exhausting to deal with. One mother in the study described her feelings about her child when she said, "It's always Matthew. It gets kind of hard for me and my kids. Everyday we're affected" (p. 444). This study showed that families whose children have disabilities and problem behaviors do experience very difficult challenges.

In addition to the emotional difficulties a child with a disability can bring into a family, problem behaviors can affect the family lifestyle. Families have difficulties making vacations enjoyable, taking care of their own physical and mental health, supporting their child in establishing a normal sleep cycle, and maintaining their energy, optimism, and health (Turnbull & Ruef, 1996). Also, relationships in the family are impaired, participation in the community decreases, and family routines change (Fox, Benito, & Dunlap, 2002). In a recent study, Fox, Vaughn, Wyatte, and Dunlap (2002) studied family perspectives on the challenges of problem behavior. They found that the problem behavior of the child affected all activities and functions of the family, such as balancing out the time with all the children, cooking, housework, and participating in the community.

Families may experience social isolation because of limited participation in the community due to feelings of discomfort about their child's behavior. A family's discomfort and fear of the child's maladaptive behavior occurring tends to intensify negative public attention (Vaughn, Wilson, & Dunlap, 2002).

Turnbull and Ruef (1996) studied family perspectives on problem behavior. The families' main perception of their children's problem behavior was constant fear of the behavior re-occurring. The families were also worried about others' reactions to their children's problem behavior. Parents were likely to escalate their own fears so that they lived in a "crisis mode," even though their child may not have had a frequent problem behavior.

Despite the difficult challenges that families face with their children's problem behavior, many families find ways to accommodate or cope with the challenges. Maul and Singer (2009) found that several families described accommodations for their children with developmental disabilities that depended on cooperation among family members. The families would work as a team, such as taking turns supervising and completing household responsibilities. Some families adapted to their child's developmental disability and problem behaviors by adjusting the time of their daily activities, such as planning schedules in advance, attending events earlier or later, and making adjustments to work schedules. Families would also seek help from behavior specialists, go to child-friendly restaurants, and avoid crowded, noisy places. When deciding on adaptations and accommodations, the families would use "trial and error," research, and good communication with other parents (Maul & Singer, 2009).

Even though parents may find their own ways to cope with the challenges that problem behaviors bring, they still desire to receive help from professionals. Turnbull and Ruef (1996) indicated that families had six major needs for support for their child with a problem behavior:

(a) assessing and gaining an adequate understanding of problem behaviors, (b) structuring home routines and home environments, (c) using strategies to enhance communication between the parent and the child, (d) expanding relationships in family, school, and community settings, (e) increasing independent choice-making, and (f) using approaches to de-escalate stress. In accordance with these findings, Turnbull and Ruef (1996) stated that families want and need “a custom-designed, multi-component, comprehensive system of supports and services” along with “a reliable alliance with dependable, trusted, and nonjudgmental helpers who provide assistance in the home and community” (p. 290–291). Families want individuals who will provide positive behavioral support and develop a collaborative partnership to help their child succeed in an inclusive lifestyle (Lucyshyn, Horner et al., 2002; Turnbull & Ruef, 1996).

Interventions to Address Challenging Behaviors

Behavioral interventions have been used for almost half a century to treat severe behavioral challenges. These interventions began with the field of Applied Behavior Analysis and have recently emerged as Positive Behavior Support principles. Each will be discussed.

Applied Behavior Analysis. Applied Behavior Analysis (ABA) was first defined in 1968 by Baer, Wolf, and Risley as the “process of applying sometimes tentative principles of behavior to the improvement of specific behaviors and simultaneously evaluating whether or not any changes noted are indeed attributable to the process of application” (p. 91). Applied research should investigate how variables can be effective in improving the behavior being studied. Baer and colleagues explained that ABA must change a socially important behavior that is observable. They recommend seven dimensions to ABA: applied, behavioral, analytic, technological, conceptually systematic, effective, and display some generality. First, the term “applied” in ABA indicates that its focus is placed on socially significant behaviors that improve the individual’s

everyday life by behaving more positively. The second dimension focuses on behavior because the target behavior needs improvement, needs to be measurable, and also needs to measure the behavior of all persons involved in the study. ABA is analytic because the behavior analyst must demonstrate effectiveness to be able to control the occurrence and nonoccurrence of the behavior. A study in ABA is technological because the procedures are precise so the study can be replicated. ABA is conceptually systematic because the procedures in the experiment are derived from basic principles for understanding and explaining human behavior. ABA is effective, meaning it produces behavior changes that reach social significance. Lastly, ABA involves studies with generality, meaning that the behavior change occurs in different environments. After more than 40 years, these seven characteristics still serve as the primary criteria for defining ABA (Cooper, Heron & Heward, 2007).

Applied Behavior Analysis focuses on using behavior change procedures that are implemented in a systematic and technological approach. The goal of ABA is to “make meaningful improvement in important behavior and to produce an analysis of the factors responsible for that improvement” (Cooper et al., 2007, p. 20). Behavior analysts discover research-based principles to help them design, implement, and evaluate behavior. For example, a classroom teacher who is trained in behavior analysis uses techniques such as positive reinforcement and stimulus fading to teach students in his or her classroom appropriate social behaviors (Cooper et al., 2007).

Positive Behavior Support. From systematic study of ABA over the last several decades, the field of Positive Behavior Support (PBS) has emerged as an approach to address the challenges that individuals with problem behaviors and their families encounter (Horner, 2000). As a developing science, PBS is defined as using “educational methods to expand an individual’s

behavior repertoire and systems change methods to redesign an individual's quality of life and, second, to minimize his or her behavior" (Carr, et. al., 2002, p. 4). The PBS approach to changing behavior differs from the early ABA approach in the following ways: PBS requires research and intervention to be conducted in natural settings (Carr, et. al., 2002), avoids using aversive consequences (e.g., inflicting physical pain to produce more meaningful outcomes), and uses a collaborative, assessment-based approach (Lucyshyn, Dunlap, & Albin, 2002).

ABA has contributed to the development of PBS in many ways. First, it contributed to PBS by providing a conceptual framework relevant to behavior change and by providing a number of assessment and intervention strategies. PBS uses the notion of the three-term contingency (stimulus-response-reinforcing consequence) from ABA. For the reduction of problem behavior, ABA helped develop educational methods such as shaping and fading, prompting, and reinforcement contingencies, which PBS has incorporated (Carr et al., 2002).

Although the focus of ABA is on the individual, PBS is generally defined as a three-tier preventative intervention model to target the needs of all children, not just children with problem behaviors. The three-tier model concentrates on the behavior and the environmental context in which the behavior occurs which aids in the development of strategies and preventative measures. This model includes a continuum of services, including universal, selected, and indicated interventions. The universal prevention tier involves defining and teaching clear expectations for behavior in all settings to all students and staff. If students demonstrate expected behavior, they are reinforced. In the selected prevention tier, approximately 10–15% of students, (e.g., students with at-risk behavior) may not respond to universal school-wide interventions. Increased structure and contingent feedback will benefit these students. The last prevention tier, indicated, involves approximately 5% of students who do not respond to either the universal or

selected interventions. It is a specialized, individualized system for students with high-risk behavior. These students receive intensive intervention support, such as functional assessment and individual behavior support plans (Reinke, Splett, Robeson, & Offutt, 2009). Although PBS can be for everyone and is commonly implemented in schools, the level of PBS intervention addressed in this study is the indicated prevention system of the three-tier model.

The individual receiving support is the most important decision maker in defining his or her goals. PBS uses the preferences from the individual to make data-based decisions. PBS also gains multiple perspectives from the people who are in close proximity to the individual with problem behavior in the development and implementation of interventions and support plans to determine replacement behaviors (Dunlap, Carr, Horner, Zarcone, & Schwartz, 2008).

PBS has become more widely known because it has been associated with federal funding and has been written into policy at the federal level (Johnston, Foxx, Jacobson, Green, & Mulick, 2006). The Individuals with Disabilities Improvement Act (2004) supports the notion of using positive behavior support and interventions for children who display problem behavior. IDEA supports training administrators, parents, teachers, related school personnel, behavior specialists, and other school staff in the use of positive behavior interventions to help prevent problem behavior (IDEA, 2004). In response to IDEA, the Office of Special Education Programs (OSEP) funded the Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS Center I) in 1997 and the second iteration of the PBIS Center (PBIS Center II) in 2003. PBIS Center II supported PBS training and research by furthering the development of school and program components needed for successful implementation of PBS (Department of Education, 2008).

PBS includes five core features that create the values and assumptions of the approach:

(a) parent-professional collaboration, (b) functional assessment, (c) family-centered goals, (d) routines, and (e) multicomponent support plans. Each will be discussed briefly.

First, parent-professional collaboration is important when considering PBS strategies to create a plan for the child with problem behavior. Family perspectives and family systems are taken into consideration when designing behavior support plans because the family is a child's most valuable and durable resource (Buschbacher et al., 2004). Also, parents are the experts about their child with a disability. The parents know the strengths, weaknesses, needs, and preferences of their child, which can help develop the best behavior plan possible (Lucyshyn, Dunlap, & Albin, 2002). The support given to the parents should reduce problem behaviors by changing the child's lifestyle that will, in turn, help improve his or her quality of life as well as the quality of life for the parents and other family members (Horner, 2000).

Second, a functional assessment helps both the professional and the parent to understand the problem behavior and to develop effective behavior support strategies. The functional assessment is the foundation for understanding the different factors of problem behavior (Horner, 2000). Lucyshyn, Kayser, Irvin, and Blumberg (2002) defined a functional behavior assessment as a "process of interviews and observations that leads to an understanding of the functions and purpose of problem behaviors, the variables that influence problem behaviors and adaptive behavior, and the strengths and preferences of the focus person" (p. 102). The functions generally include four categories: (a) avoid or escape unwanted demands, tasks, or people; (b) obtain acknowledgement; (c) communicate wants or needs; and (d) engage in self-stimulation (King-Peery & Wilder, 2005; Lucyshyn, Horner et al., 2002).

Third, attention to family-centered goals, values, and resources is important to create plans that fit with the family. This helps acknowledge the family as the unit of attention. Also, if

the plan fits with the family, the family is more likely to accept the plan and implement it (Lucyshyn, Horner et al., 2002).

Fourth, using the daily and weekly routines and activities for intervention settings provides essential contexts for child development and learning. PBS promotes both behavioral and lifestyle change: therefore, the assessment of the routines and activities helps in defining the family's challenges and developing a behavioral support plan that is congruent with the family's goals, needs, and time (Lucyshyn, Kayser, Irvin, & Blumberg, 2002).

Lastly, multicomponent support plans help create effective family contexts. The plans include preventive, teaching, and consequence strategies that address the setting event, antecedent, and function of the problem behavior. The multicomponent plan may include the setting event, preventive strategies, antecedents, consequences, and teaching strategies to help make the problem behavior ineffective, efficient, and irrelevant (Lucyshyn, Horner et al., 2002; Horner, 2000). O'Neill et al. (1997) stated that a rule in effective behavior support is to "not propose to reduce a problem behavior without also identifying the alternative, desired behaviors the person should perform instead of the problem behavior" (p. 71). Because the goal for the individual is to have a lifestyle change, the behavior support should be structured and comprehensive in highly controlled contexts. The behavioral intervention should include social systems to build schools' and communities' ability to teach behavior support efficiently (Horner, 2000).

Training Parents to Use Positive Behavior Supports

With more than 30 years of research on behavioral approaches, PBS parent training has evolved to improve behavioral parent training programs to help families who are raising children with challenging behaviors (Singer, Goldberg-Hamblin, Peckham-Hardin, Barry, & Santarelli,

2002). The behavioral parent training literature shows that parents can learn behavioral techniques to help reduce their child's challenging behavior (Buschbacher, Fox, & Clarke, 2004). In order to teach parents PBS strategies, professionals have implemented PBS within the home and during family routines.

Training parents at home. Positive behavior support has become an effective approach for addressing the problem behavior of individuals with disabilities (Buschbacher, Fox, & Clarke, 2004). Buschbacher and colleagues (2004) found that PBS parent-implemented, in-home interventions are effective in reducing behaviors, such as hitting, biting, pinching, and slapping. Vaughn et al. (2002) concluded that a PBS family-centered approach that includes active involvement from a parent does reduce disruptive behavior, such as climbing chairs and tables in a public context.

Because parents offer so much knowledge about their child with problem behaviors, many studies have been conducted with training parents about PBS in the home. Buschbacher et al. (2004) conducted a study with Samuel, a 7-year-old boy with autism, on the effectiveness and durability of PBS within the home and with family members. Samuel presented many challenging behaviors such as slapping, pinching, biting, screaming, and kicking. Buschbacher et al. (2004) followed PBS procedures in routine meetings with the family and the interventionist. To understand the child's strengths and needs, a person-centered planning meeting was conducted, which included everybody who was able to support the child and his family in achieving an improved quality of life. In collaboration with the interventionist, the family identified triggers for their child's problem behavior, identified possible setting events, and developed hypotheses for the behavior. The PBS process with the family included functional assessment, collection of baseline data, development of the function of the challenging

behaviors, development of interventions based on the data taken, implementation of interventions, and social validation data. Throughout the entire study, Samuel's family was actively involved in the assessment and implementation process. The parent-professional collaboration helped develop a positive communication-based intervention, which helped reduce the problem behavior and improve the child's life (Buschbacher et al., 2004).

Lucyshyn et al. (2007) conducted a longitudinal, single-case study with Katherine, a girl with autism and severe problem behavior to examine the efficacy, social validity, and durability of a positive behavior support approach. Five of Katherine's problem behaviors were chosen for the study and they included high-pitched screaming or screeching, physical resistance to parental assistance, leaving her assigned area by running away during a task, disruptive or destructive behavior, and physical aggression. The study was conducted across four settings: dinner routine, going to bed routine, restaurant routine, and grocery shopping routine. The positive behavior support plan included setting event strategies, antecedent strategies, teaching strategies, and consequence strategies for the family to use across all settings. The implementation plan included parent training and support activities to help implement the positive behavior support plan. The parents enacted the plan with constant help from the professionals. Following the PBS plan, Katherine's problem behaviors decreased to zero or near zero levels. The support process also showed an improvement in Katherine's quality of life. She showed improvement in participation in community activities. Not only did the support help Katherine, but it also improved her parents' quality of life and personal health. As their knowledge grew regarding PBS strategies, they became less anxious about participating in community activities with Katherine, such as shopping and going to church. Throughout the study, the parents found that PBS was helpful and adaptable from early childhood to middle adolescence. This study showed

the effectiveness of a PBS approach in families that have children with developmental disabilities and severe problem behavior (Lucyshyn et al., 2007).

PBS procedures within the home depend on the continued development and use of parent-professional collaboration because the parents provide information and data to help validate the effectiveness of behavior interventions (Albin, Dunlap, & Lucyshyn, 2002).

However, parent-professional collaboration poses several challenges. Because PBS requires time and commitment, professionals may find it difficult to spend time planning and developing individualized interventions with the families. Also, some families may feel intimidated or judged by professionals, which prevents the families from building trusting relationships with professionals.

Not only does parent-professional collaboration face challenges, but in-home parent training faces challenges also. High levels of family stress, low socioeconomic status, social isolation, negative social networks, marital discord, and parental depression are variables that may interfere with in-home parent training. Due to these limitations, it is important to discover other ways in which professionals and families can collaborate within a process and gain rapport and trust, yet will still be effective in promoting behavior change, such as a workshop.

Training parents in community settings. PBS has also become a fundamental approach for addressing problem behaviors in public contexts. Vaughn et al. (2002) conducted a study using PBS principles with a family raising a 7-year-old son, Tolu, with autism. The family had a difficult time eating out at fast-food restaurants because of Tolu's challenging behavior. Tolu would climb on the restaurant's tables and chairs. A functional assessment was conducted to identify the function of the problem behavior, along with a reinforcer assessment to decide which toys to use for the intervention. The parents conducted the intervention plan. The intervention

was divided into three different subroutines: arrival, mealtime, and departure. During each subroutine a highly preferred reinforcer was used to keep Tolu's attention and interest. The result of the study showed that using a family-centered PBS approach helped decrease disruptive behavior (Vaughn et al., 2002).

Training parents through workshops. A workshop delivery is one way to teach parents in a group setting. It is a way to train parents to implement specific procedures that they can use at home. "Parent training is a treatment approach that uniquely positions the therapy model toward a goal of generalization to the home and other relevant community settings." (Matson, Mahan, & LoVullo, 2009, p. 962). (Matson, Mahan, & LoVullo, 2009). Generally, the parents, not the child, are the ones to participate in the treatment. If the parents' behavior changes throughout the treatment, the child's behavior is likely to improve (Nix, Bierman, & McMahon, 2006).

Nixon (2002) considered parent management training (PMT) to be one of the best evaluated and effective interventions for children's behaviors because it uses the parents as the primary agent for change, due to their daily influence on their child's behavior. PMT teaches parents to manage their children's behavior through behavior modification. The parents are taught the principles of reinforcement. They are also instructed on identifying antecedents and consequences to their child's behavior (Nixon, 2002).

Borrego and Burrell (2010) conducted a study applying the behavioral parent training program, Parent-Child Interaction therapy (PCIT), with children with problem behaviors. It focuses on both the parent and the child, so that the parents can use the skills they are learning in treatment. In PCIT, an assessment is conducted before the treatment to gather information on the child's problem behavior. The therapist interviews the parents and other primary caregivers to

help come up with a behavior plan. Another phase of the pre-assessment is for the therapist to observe the relationship between the parent and the child for 15 minutes. After the assessment, the parents attend their first session that focuses on enhancing the relationship between the parent and child called the Child-Directed Interaction (CDI) phase. The parents learn to develop positive parent-child interactions and attend to prosocial behaviors. During the week, parents are given homework to have a “special play time” for 5-minutes to help them practice their positive skills with their children. After the parents pass the CDI stage, they are introduced to the Parent-Directed Interaction phase, which teaches about child management skills, such as being consistent in following through with positive consequences for compliance. Throughout the PCIT training, parents are given support from the therapist. The parents are given a clear rationale on why the training is important. The therapist guides them through the process by modeling the skills with the child (Borrego & Burrell, 2010).

Borrego and Burrell used the PCIT training on a 3-year-old boy named Matthew who was referred for the training by his pediatrician. Matthew’s foster parents reported that he had oppositional behavior, such as not following the rules, temper-tantrums, aggression with younger siblings, yelling, whining, and crying. Matthew’s day care teachers reported his problematic behaviors were hitting and throwing objects at other children and also being off-task. Spanking, time-out, restriction of privileges, and threats were the discipline strategies that were being used by his foster parents for his problem behaviors. During the first session, Matthew was diagnosed with Oppositional Defiant Disorder. The foster parents were then taught the CDI skills, such as praise and ignoring attention-seeking and inappropriate behaviors. The foster parents were concerned about implementing the techniques at home, however after a couple more sessions, the foster parents felt comfortable with the new techniques. After the fifth PDI coaching session,

the foster parents saw improvements in Matthew's behavior at home. Matthew's behavior at school also improved. He no longer displayed severe behavior problems (Borrego & Burrell, 2010).

Many benefits exist for training parents through the workshop model. Some parents who enroll in parent workshops find it to be opportunity to meet other parents that share similar experiences and feelings (Dumas, Nissely-Tsiopinis, & Moreland, 2006). Parents are often the best resources for other parents who are raising a child with the same disability and challenging behaviors (Santelli, Ginsberg, Sullivan, & Niederhauser, 2002). One way for the training to be effective is if the parents attend the sessions in a meaningful way. This means they must listen attentively, try to understand the new ideas, be receptive to new ways of interacting with children, ask questions appropriately, actively participate, and attempt to use the new ideas in their daily routines (Nix et al., 2006).

Parent workshops may also show limited benefits. Parents experiencing stress and high levels of adversity are at risk for poor attendance to the meetings and lack of participation. They also have difficulty following up on homework and maintaining treatment gains over time (Chaco, Wymbs, Wymbs, et al., 2009). If parents have to travel long distances or miss work to attend the workshop, they may feel that the workshop is too inconvenient. Also, if parents lack the time for the parent workshops, due to work or other activities, they are less likely to participate (Singer et al., 2002).

Children with developmental disabilities often show evidence of a wide range of problem behaviors, such as tantrums, self-injury, and physical aggression, because of their learning deficits in non-verbal and verbal language, cognition, expressing emotions, and social interaction. Raising a child with a disability and problem behaviors can be very challenging for

families. The quality of life for the families is inflicted with stress, depression, physical exhaustion, social isolation, and marital distress because of the difficulties of raising a child with a disability and problem behaviors. Even though it is challenging, families learn to adapt and cope with the challenges by depending on each other. However, families still desire the need to receive help from professionals on how to manage and create effective strategies for long-term durable behavior change. One effective approach to treat behavior problems is PBS, which is a positive systems change method to transform an individual's quality of life by decreasing the problem behavior. Parents can be trained by professionals in the home, in community settings, and through workshops to use the PBS approach to address their child's problem behavior. Several studies on PBS have been conducted in the home and using only one family. This study contributes to the literature because PBS was taught in a workshop approach with seven different families.

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APPENDIX B

Instruments

Parent-Child Relationship Inventory

The Limit Setting subscale of the PCRI includes the following 12 statements.

1. I have trouble disciplining my child.
2. I have a hard time getting though to my child.
3. My child is more difficult to care for than most children.
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.

Parental Support of the PCRI scale includes nine statements, with items four, eight, and nine reverse coded. All questions are rated on a Likert scale: 1=strongly agree, 2=agree, 3=disagree, and 4=strongly disagree.

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.

Scales of Independent Behavior – Revised Behavior Problem Scale

Frequency: How often does this behavior usually occur?

0. Never
1. Less than one month
2. One to 3 times a month
3. One to 6 times a month
4. One to 10 times a day
5. One or more times an hour

Severity: How serious is the problem usually caused by this behavior?

0. Not serious; not a problem
1. Slightly serious; a mild problem
2. Moderately serious; a moderate problem
3. Very serious; a critical problem
4. Extremely serious; a critical problem

Problem Behavior Categories

Hurtful to Self: *Injures own body*—for example, by hitting self, banging head, scratching, cutting or puncturing, biting, rubbing skin, pulling out hair, picking on skin, biting nails, or pinching.

Hurtful to Others: *Causes physical pain to other people or to animals*—for example, by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object.

Destructive to Property: *Deliberately breaks, defaces or destroys things*—for example, by hitting, tearing, or cutting, throwing, burning, marking or scratching things.

Disruptive Behavior: *Interferes with activities of others*—for example, by clinching, pestering or teasing, arguing or complaining, picking fights, laughing or crying without reason, interrupting, yelling or screaming.

Unusual or Repetitive Habits: *Unusual behaviors that may be done over and over*—for example, pacing, rocking, twirling fingers, sucking hands or objects, twitching (nervous tics), talking to self, grinding teeth, eating dirt or other objects, eating too much or too little, staring at an object or into space, or making odd faces or noises.

Socially Offensive Behavior: *Behavior that is offensive to others*—for example, by talking too loud, swearing or using vulgar language, lying, standing too close or touching others too close or touching others too much, threatening, talking nonsense, spitting at others, picking nose, belching, expelling gas, touching genitals, or urinating in inappropriate places.

Withdrawal or Inattentive Behavior: *Difficulty 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.

Uncooperative Behavior: *Behavior that is uncooperative*—for example, refusing to obey, do chores, or follow rules; acting defiant 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.

APPENDIX C

Instruments: Qualitative Data

Family Information Questionnaire (One per family)

ID# _____

- (1) Today's Date _____
- (2) Family ethnicity _____
- (3) Ethnicity of child with disability (if different from family) _____
- (4) Child with a disability's birthday _____ Age _____ Gender _____
- (5) Initials of sibling who participating in the study _____
- (6) Sibling's Birthdate _____ Age _____ Gender _____
- (7) Please list the initials of the first names of all other children in your family (do not include sibling listed above or child with a disability).

<u>Name</u>	<u>Male/Female</u>	<u>Age</u>	<u>Birthdate</u> (Month/Day/Year)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

(8) Family Composition: (circle one)

- | | |
|-------------------------|--|
| 1. Two Parent Family | 4. Other Family Type _____ |
| 2. Single Parent Family | 5. Other adults besides parent living at home? Y N |
| 3. Step Parent Family | 6. If yes, who? _____ |

(9) Age of Parents: _____ Father _____ Mother

(10) How many years of education has husband complete? _____ years

(11) How many years of education has wife completed? _____ years

(12) What is husband's current occupation? (job title) _____
Please briefly describe husband's duties _____

(13) What is wife's current occupation? (jobtitle) _____
Please briefly describe husband's duties _____

(14) If husband has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

(15) _____ Number of hours husband works per week.

(16) If wife has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

(17) _____ Number of hours wife works per week.

(18) _____ Husband's religious preference.

(19) _____ Wife's religious preference.

(20) What is your total family income?

1. under \$7000

3. \$15001-25000

5. \$35001-50000

2. \$7000-15000

4. \$35001-35000

6. Over \$50000

(21) Please describe your child's disability

Date _____

ID # _____

Child with Special Needs Description Adaptive Skills/Levels of Supports

Please rate your child's need for support in the following areas, based upon the following criteria:

- 1 = Intermittent:** Supports are provided on an "as needed" basis, *temporary, infrequent* or *short-term*, in a few settings.
- 2 = Limited:** Supports are provided on a *regular basis* for a *short period* of time (not of an intermittent nature), in several settings.
- 3 = Extensive:** Supports are needed *regularly* (e.g., daily) in several settings and may extend over *long periods* of time.
- 4 = Pervasive:** Supports are *constant* and *intense* in all settings. They may be life-sustaining.

- _____ 1. **Communication** (understand others and express self)
- _____ 2. **Self-Care** (toileting, eating, dressing, hygiene, grooming)
- _____ 3. **Home Living** (clothing care, housekeeping, cleaning, cooking, home safety)
- _____ 4. **Social Skills** (interact with others appropriately, cope with demands, obey rules, peer acceptance)
- _____ 5. **Community Living** (travel, shop, use public facilities, church, volunteer)
- _____ 6. **Self-Direction** (make choices, follow a schedule, seek assistance, resolve problems)
- _____ 7. **Health & Safety** (eating nutritiously, illness identification, basic first aid, physical fitness, taking medication, receiving home health care, follow rules and laws)
- _____ 8. **Academics** (writing, reading, math, science, health, geography, social studies)
- _____ 9. **Leisure** (play, recreational activities, personal choices)
- _____ 10. **Work** (part or full-time job, related work skills, money management, changing job assignments)
- _____ 11. **Mobility** (ability to get from one place to another, visit friends and family)

Classification & Intellectual Functioning

12. What is your child's *primary* diagnosis?
13. What *educational classification* is listed on his/her Individualized Educational Program (IEP)?
14. Please list *secondary* diagnoses.

What is your child's approximate IQ level?

___ Unknown ___ Unable to determine

___ <25 ___ <40 ___ <55 ___ <70 ___ <85 ___ <100 ___ <115 ___ <130 ___ <145 ___ >145

Physical Health, Mental Health, Etiology Considerations

15. Please list any physical health related conditions your child has.
16. Please list any psychological or emotional difficulties (e.g., mental illness) your child experiences.
17. Please list the cause of your child's condition (if known) and your child's age when diagnosed.

Environmental and Cultural Contexts

Rate the extent to which your child's living, leisure, and educational environments *facilitate* or *restrict* opportunities for community presence/participation, making choices, demonstrating competence, and gaining respect.

Environments	Facilitate				Restrict
Home	1	2	3	4	5
Neighborhood	1	2	3	4	5
School	1	2	3	4	5

APPENDIX D

Consent Form

Family ID: _____

Participation and Consent to be a Research Subject Brigham Young University Family HOPE Project

Background: A group of faculty at Brigham Young University is studying families of children with developmental disabilities. The primary purpose of this project is to determine how families learn to provide positive behavior support to their children with developmental disabilities. The purpose of this consent form is to formally ask you, your child with a disability, and one of your school-aged children who does not have a disability, to assist us and to obtain your consent.

Study Procedure: This research project has two parts. First, we will obtain information from both parents. Parents will complete questionnaires, and be interviewed for approximately 60-90 minutes. We will then provide school-based training to support your efforts to teach your child with a disability how to have more acceptable behavior. Following 8-10 weeks of this training, you will be interviewed again.

The second part of the project involves obtaining information from one of your nondisabled school-aged children by having them answer some questions and keep a daily diary, including a drawing, for two weeks.

Confidentiality: Project personnel will work with you in a professional manner, 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 project personnel has reason to believe that such abuse, neglect, or exploitation has occurred, they will report this to Child Protective Services (CPS), Adult Protective Services (APS) or to the nearest law enforcement agency.

Risks: There are few risks associated with the study. 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 BYU student assigned to you or the designed behavioral intervention, you may call Dr. Tina T. Dyches, Principal Investigator at (801) 422-5045. Daily journals and drawings may be utilized in professional publications and presentations, but no names will be used. Video recordings of training sessions may be used for future trainings or follow-up, but participants will not be identified.

Voluntary Participation: Participation is voluntary and you may withdraw at any time without penalty or loss of benefits. Signing and returning this form will place you on a research study participation waiting list. The number of families that will participate will be determined by the number of BYU students available. If your family is not selected for the current semester

training, you will be placed on a waiting list for the next study.

Benefits: Your participation in this project will provide valuable information in the effort to determine the issues surrounding parent training. Information obtained from this study will eventually be used by parents, teachers, and other professionals to help families raising children with disabilities.

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 for implementing these plans for your child. Families who complete participation in the study will receive a \$25 gift certificate to compensate them for their time. Families who record behavior progress of their child will receive \$20 upon submission of these data. Families on the waiting list will receive \$25 for participating in the pre- and post-test data collections.

Contact Persons: If you have any questions regarding this project please contact Dr. Tina Taylor Dyches at (801) 422-5045 or tina_dyches@byu.edu.

Institutional Review Board: If you have questions about your rights as participants in the study you may call the Institutional Review Board at (801) 422-1461 or email irb@byu.edu (BYU IRB Administrator, A-285 ASB, Brigham Young University, Provo, UT 84602).

Authorization: I have read the above and understand the inconveniences, risks, and possible benefits of the study. I agree to the participation of myself and members of my family. I agree to allow use of my child's daily journals and drawings by project staff, and understand these will become the property of the researchers and may be published without use of names.

I agree to the participation of myself and my children listed below:

_____ Date _____
Mother

_____ Date _____
Father

_____ Date of Birth _____
Child with Disability

_____ Date of Birth _____
Child without Disability