

CARETAKERS' PERCEPTIONS OF IMPLEMENTING APPLIED BEHAVIORAL
ANALYSIS WITH THEIR CHILDREN

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CARETAKERS' PERCEPTIONS OF IMPLEMENTING APPLIED BEHAVIORAL
ANALYSIS WITH THEIR CHILDREN

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Abstract
of
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The primary purpose of the research is to understand the difficulties as well as successes parents have with the implementation of applied behavioral analysis (ABA) with their autistic child. The study participants were a convenience sample of parents and/or caregivers whose child has a diagnosis of autism and who receive educational services through Yolo County Office of Education. Four parents/caretakers volunteered to be interviewed and the interviews were taped, professionally transcribed and analyzed for common themes/concerns. Four main themes were identified in the interviews. Study participants discussed strategies and techniques for implementing ABA and gave examples of how their home and family were modified and adjusted in order to implement it. Implications for both service providers and parents with autistic children are discussed. Social networking and communication among parents is important for the successful implementation of ABA.

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Date

DEDICATION

This project is dedicated to my husband, Mario, and to my mom, Sue, for their love, encouragement, and support through this long journey. Without them this would not have been possible.

TABLE OF CONTENTS

	Page
Abstract	iv
Dedication	v
Chapter	
1. THE PROBLEM	1
Introduction	1
Background of the Problem	2
Statement of the Research Problem	4
Purpose of the Study	5
Theoretical Framework	5
Definition of Terms	7
Assumptions	8
Justifications	9
Limitations	10
2. LITERATURE REVIEW	11
Introduction	11
Autism	11
Interventions	14
TEACCH	14
Speech Therapy	15
Occupational Therapy	16
Sensory Integration Therapy	17
Relationship Development Intervention	18
Alternative Treatments	18
Verbal Behavior Intervention	19
Applied Behavioral Analysis Background	20
Discrete Trial	22

Early Intervention	23
Limitations of Applied Behavioral Analysis	24
3. METHODS	26
Introduction.....	26
Design	26
Procedure	27
Data Analysis	27
Protection of Human Subjects	28
4. FINDINGS	29
Introduction.....	29
Participants.....	29
Parent Number One.....	30
Parent Number Two.....	30
Parent Number Three.....	30
Parent Number Four.....	30
Emerging Themes	31
Impact on Family Relations	38
Alternative Treatments.....	39
Sensory Integration	39
Summary	41
5. CONCLUSION.....	42
Appendix A: Parental Consent Form.....	49
Appendix B: Interview Questions	50
Appendix C: Demographics of Study Participants	51
References.....	52

Chapter 1

THE PROBLEM

Introduction

Autism is the most common of the Pervasive Developmental Disorders, affecting an estimated 1 in 150 births (Center for Disease Control Prevention, 2007). This means that as many as 1.5 million Americans today are believed to have some form of autism, and this number is on the rise (Autism Society of America, 2007). Based on statistics from the U.S. Department of Education (2007) and other governmental agencies, autism is growing at the startling rate of 10-17% per year. Autism knows no racial, ethnic, or social boundaries; family income; lifestyle; or educational levels, and can affect any family and any child. Even though the overall incidence of autism is consistent around the world, it is four times more prevalent in boys than in girls (Autism Society of America, 2007).

The researcher became interested in this topic after working with and teaching individuals with autism within the educational system. Many behavioral teaching strategies and components for working with individuals with a diagnosis of autism were learned by the researcher, including applied behavioral analysis (ABA), which is a treatment approach that breaks down skills into pieces small enough for a child to understand and then are repeated over and over until they become part of the child's behavior (Autism Web, 2010). The researcher hopes to contribute to the knowledge of teaching strategies for individuals with autism. Understanding the use of ABA and the difficulties with its implementation for caregivers can both enhance the effectiveness of

this strategy and contribute to the decisions which are made by the parents of young children with autism. ABA shows an increase in the potential for autistic individuals to become more high functioning and more independent than those children without these teachings (Autism Society of America, 2007). However, for ABA to be optimally effective, it is extremely important to be consistent with every detail of the intervention (National Autistic Society, 2007). The researcher's own experience has been that parents often have difficulty implementing the detailed components required of ABA in different environments, such as at home. In order to increase the effectiveness of ABA, it is critical to better understand the experiences of parents of autistic children in applying ABA in different settings. To date, there have been no studies that have examined the difficulties parents experience with the implementation of ABA in settings other than school. It is hoped that the present study will elucidate some of these issues and provide direction to service providers so that they can better assist parents of autistic children in the implementation of ABA.

Background of the Problem

Autism now accounts for 45% of all developmental disabilities within California and over the past fifteen years there has been a significant rise in autism from 1 per 2,500 in 1970 to 1 per 285 in 1999 (National Autistic Society, 2007). Although there have been multiple hypotheses including biological and environmental ideas for the cause of autism, there is no known cause or cure. Due to the multiple possibilities that are involved with autism, there could be multiple reasons for the increase in individuals with autism. Treatment of these children often takes a multidisciplinary approach. This disability is

extremely complex and has multiple severities, which accounts for the varying capabilities of individuals with autism.

Currently, there is no known cure for autism, although there are many treatment approaches in which children with autism learn more independence and communication skills. Many studies have revealed the successful application of ABA, and some theorists believe the only data that shows consistent improvements with autistic children is ABA (Schoen, 2003). It is possible for autistic children to learn their needs (sensory, behavioral, and environmental) and to be able to control them in order to be taught in a regular education classroom. When children are taught to control their sensory, behavioral and environmental needs within the intensive behavioral teachings, their ability to learn increases. Also, this will give them the opportunity to learn to communicate effectively. Often, children with autism are non-verbal, and within these intense behavioral sessions a communication system other than verbal communication can be introduced.

Children diagnosed with autism do not follow the typical patterns of child development but demonstrate deficits in social interaction, verbal and nonverbal communication and repetitive behaviors or interests (National Institutes of Mental Health [NIMH], 2004). These features will present differently in each individual child. Each child will display communication, social, and behavioral patterns that are unique to the child but fit into the overall diagnosis of autism (NIMH, 2004). Some of the common signs of autism are a) reduced sensitivity to pain, but abnormal sensitivity to sound, touch, or other sensory stimulation; b) engagement in repetitive movements such as

rocking or twirling; c) self-abusive behavior such as biting or head-banging; and d) difficulty interpreting social cues (National Institute of Neurological Disorders and Stroke [NINDS], 2005). Autism varies widely in its symptoms and severity in each child.

There are multiple treatment theories and interventions for autism, including sensory integration theories, speech therapy, occupational therapy, relationship development intervention, verbal behavior intervention, ABA, and alternative treatments. There is no single treatment protocol for all children with autism, and each child responds differently to treatment, although most children respond best to highly structured programs (Autism Speaks, 2007). Extensive research is being done including investigations into causes, diagnosis, early detection, prevention and treatment (NINDS, 2005).

According to the National Institutes of Mental Health (2004), most professionals do agree that early intervention is important, and that most individuals with autism respond well to highly structured, specialized programs such as ABA treatment (NIMH, 2004). Unfortunately, little is known regarding parents and other caregivers' experiences in implementing these techniques in the home environment.

Statement of the Research Problem

Applied behavioral analysis is an intensive therapy which involves instruction that is directed by adults in a highly structured fashion (Autism Speaks, 2007). The original form of ABA was designed by Ivar Lovaas, mainly for parents who have children with autism (National Autistic Society, 2007). Lovaas began his work with

institutionalized, non-verbal children who had been diagnosed as autistic in the late 1960s and 1970s, and eventually worked with parents and children in their home setting (National Autistic Society, 2007). Parents and children were observed in the home setting to ensure that the new skills learned were maintained. The children participating in the Lovaas treatment received 40 hours a week of structured input on a one-on-one basis from trained students whose work was closely supervised by Lovaas and his staff, in addition to the parent's participation in the treatment (National Autistic Society, 2007). The present research aims to understand the difficulties and successes that parents experience regarding the implementation of ABA. A review of the literature indicates that little is known about the issues parents face regarding the use of ABA.

Purpose of the Study

The primary purpose of the research is to understand the difficulties as well as successes parents have with the implementation of ABA with their autistic child. The researcher seeks to better understand the adaptations, alternative techniques, frustrations and successes that parents and caregivers face in using this program. The present study may aid both service providers and parents with autistic children in finding strategies and techniques for being consistent with ABA treatment therapy.

Theoretical Framework

Four theoretical frameworks are used to guide this study: a) systems theory, b) ecosystems theory, c) ecosystems perspective, and d) grounded theory. Systems theory suggests that to understand an entire system, each member should not be viewed in isolation, but should be understood as a group (Greene, 1999). What this means for a

child with autism is that his/her personal biological makeup, interactions with individuals, family interaction, and environment will be understood as an entire entity rather than individually. Even though “different people may react differently to the same environment and the same environment may interact differently with the same person at different times” (Greene, 1999 p. 268), it is important to understand that individuals with autism are affected by behavioral influences of other individuals and environmental stimuli. Understanding each individual within a system and viewing each as a whole will help understand how individuals with autism are affected by their environment and relationships. Individuals with autism play a large part in family systems with interdependence and differentiated roles being established.

Ecosystems theory was utilized to understand the structure of interacting and interdependent persons and differentiated roles of individuals involved (Greene, 1999). This aided in understanding the multiple areas which influence autistic individuals and the connections between the four system levels: a) microsystem, b) mesosystem, c) exosystem, and the d) macrosystem (Greene, 1999). The research was conducted on the microsystem and mesosystem levels, including understanding of family, school, and environmental interaction and influence. At the microsystem level the child’s immediate social settings including home and school will be assessed, attempting to understand the child’s behavioral reactions to individuals and environmental stimuli. At the mesosystem the research attempted to understand the communication between the child’s school and home relationships with treatment interventions and the effectiveness of each piece.

The ecosystems perspective (Greene, 1999) was also a theory which was utilized while conducting the research. There are multiple theories about the causality of autism, which deal greatly with the environment. This theory aided in viewing the environmental and emotional factors which involve the families and environments of autistic children.

Grounded Theory was used to guide this qualitative study. Each similar case was looked at separately and the outcomes were compared to see where the differences and similarities are evident (Glaser & Strauss, 1967). This theory aided the researcher in viewing the data with no preconceived notions. This approach begins with observations rather than hypotheses and seeks to discover patterns and develop theories from the ground up (Rubin & Babbie, 2005). Grounded theory has no preconceptions, although some research may build and elaborate on earlier grounded theories (Rubin & Babbie, 2005). This study aimed to understand patterns in parents' and/or caregivers' perspective of applied behavioral analysis.

Definition of Terms

Applied Behavioral Analysis (ABA): A therapeutic intervention and scientific approach to understanding behavior and how it is affected by the environment. The most basic skills most individuals learn naturally are broken down into pieces small enough for a child to understand and then are repeated over and over until they become part of the child's behavior (Autism Web, 2010).

Autism: A developmental disability that affects the way a person communicates and relates to people around him/her. Individuals with autism have difficulties with everyday social interactions (National Autistic Society, 2007). People with autism generally

experience three main areas of difficulty, including social interaction, social communication, and social imagination (National Autistic Society, 2007).

Discrete Trial Training: A presentation of a series of trials to the child, each consisting of a specific cue or instruction from the adult, an opportunity for the learner to respond, and a consequence delivered by the adult depending on the child's response.

Prompt or cue: A signal used to prompt another action, such as a touch on the shoulder or saying the individual's name. This prompt will remind the individual of the action which is asked of him/her.

Reinforcing stimulus: An object or action which increases the likelihood of the correct response, whether to strengthen or weaken a behavior. Each individual will have a different reinforcing stimulus they prefer such as food or physical activity.

Target stimulus: The desired response of a situation or a cue.

Assumptions

Assumptions used in the research study include the following:

1. All research participants have a child with autism in a public school that provides appropriate education.
2. Every child with a disability has the right to have the best treatment possible for him/her in an educational environment.
3. The Individuals with Disabilities Education Improvement Act mandates that the state provide all eligible children with free and appropriate public education that meets their unique individual needs. This law legally entitles children with disabilities the ability to receive early intervention services or special education

services if the child meets the state eligibility requirements that define disability (Autism Speaks, 2007).

4. Parents participating in the research study are familiar with ABA and their child's educational plan.
5. All research participants are assumed to feel comfortable with providing honest experiences and testimonials regarding their difficulties and successes surrounding ABA.

Justification

The Social Worker's Code of Ethics is used as justification for children having the right to the best treatment option available. Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to individuals with disabilities (U.S. Department of Education, 2007). The more education and understanding parents have of services and treatments available to children with disabilities, the better they can communicate and work effectively with service providers and educators to provide optimal treatment for their children. It is important to document parents' experiences of treatment programs and educational experiences, because without their input, it is difficult to understand the successes and difficulties that the parents and/or caregivers have with children who are autistic.

Limitations

The major limitation of this study is its sample size, which limits the generalizability of the findings. However, given that the author has found no prior published studies examining parents/caregivers experiences and difficulties implementing ABA, it is hoped that the study findings may be used to generate hypotheses which could be tested using larger samples.

Another limitation includes sample bias. The study consists of voluntary participants who presumably are parents with knowledge about autism and ABA. Parents with more difficulty implementing the treatment program or less knowledge about the approach may be reluctant to participate. In addition, the researcher is monolingual and bilingual parents may not feel comfortable volunteering due to the language barrier.

Chapter 2

LITERATURE REVIEW

Introduction

This chapter contains the literature review, with an explanation of autism's common signs and characteristics, and how a person is diagnosed with autism. Second, interventions available to families and children with autism are reviewed, and then the background of ABA and the basic science involved with this type of intervention for individuals with autism is explained. Discrete trial teaching is then examined indicating the complexity of the applied behavioral analysis intervention. Finally, the importance of early intervention is made clear, followed by the limitations of the intervention using ABA.

Autism

Clinical research has not been able to identify any single cause of autism; subsequently, interventions have varied considerably with attempts to modify emotional, educational, medical, and behavioral symptoms (Schoen, 2003). With the intention of modifying wanted or unwanted behavior, ABA-based programs are reported by the Surgeon General of the United States to be the most effective intervention for individuals with autism (Rosenwasser & Axelrod, 2002). The idea of applied behavioral analysis is based on the theory that behavior which is rewarded is more likely to be repeated than behavior which is ignored (Greene, 1999).

According to Dr. Gary Goldstein (Autism Speaks, 2006), autism is part of a group of disorders known as Autism Spectrum Disorders, which is a complex neurobiological

disorder that typically lasts throughout a person's lifetime. The disorder is characterized by varying degrees of impairment in communication skills and social abilities, and also by repetitive behaviors. Autistic symptoms range from mild to severe, with Asperger Syndrome being one of the milder forms of the disorder. Other developmental disorders that fall under the Autism Spectrum Disorders are Rett Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Childhood Disintegrative Disorder (Autism Speaks, 2007).

Being a spectrum disorder, autism manifests itself in many different forms. Autism can range from mild to severe, and though children who are on the spectrum are likely to exhibit similar traits, each child is unique, managing to have a variety of symptoms (Autism Speaks, 2007). Many children with autism engage in repetitive movements such as rocking and twirling, or self-abusive behavior such as biting or head-banging. Many children also have a reduced sensitivity to pain, but are abnormally sensitive to sound, touch, or other sensory stimulation. The over stimulation of a child's sensory system may contribute to behavioral symptoms, such as a resistance to being cuddled or hugged (Autism Speaks, 2007). The receptive and expressive language in children with autism have varying degrees, with some only showing slight delays, such as difficulty holding a conversation, rather than speaking in a monologue about an obsessive interest. Others may have great difficulty learning to talk or read (Autism and PDD Support Network, 2006). According to the Autism Society of America (2007), "Two children, both with the same diagnosis, can act completely different from one another."

Parents are typically the first to notice symptoms of autism in their child. Some parents describe a child that seemed different from birth, while others describe a child who was developing normally and then lost skills (Autism Speaks, 2007). A child with autism may appear to have normal development, meeting appropriate developmental milestones, and then withdrawing and becoming indifferent to social engagement (NINDS, 2005). Individuals with autism have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, they do not watch other people's faces for clues about appropriate behavior, and they often lack empathy (NINDS, 2005). The expressions communicated on one's face can be visually over-stimulating for an individual with autism, resulting in the lack of eye contact.

Parents' observations play a key role in the diagnosis of a child. In evaluating a child, doctors rely on the behavioral characteristics, observational data, and multiple developmental screening tools to make a diagnosis. Usually, a team of specialists including a neurologist, psychiatrist, developmental pediatrician, psychologist, gastroenterologist, audiologist, speech therapist, occupational therapist, and other professionals are included in making the diagnosis (Autism Speaks, 2007). Due to the fact that there is no medical test or biomarker for autism, a majority of the diagnoses are based on observations of the child's behavior, educational and psychological testing, and parent reporting (NINDS, 2005).

For parents, learning their child has autism is devastating, even if they suspected something was wrong. Unlike other diseases, autism carries no defined treatment

protocol, and parents are often on their own to begin learning treatments, interventions, and therapies to determine which intervention approach might be best for their child (Schriebman, 2000). It is important for parents to understand and be knowledgeable about different treatment options and their child's educational rights.

Interventions

There are many different intervention therapies for children with autism including occupational therapy, sensory integration therapy, speech therapy, verbal behavior intervention, and alternative treatments. The multidisciplinary team and parents must work together in developing an appropriate intervention plan for a child. Due to autism being a spectrum disorder and the varying severity each child may manifest, interventions vary among children based on their behaviors and abilities.

TEACCH

TEACCH (Training and Education of Autistic and Related Communication Handicapped Children) is a special education program that is tailored to the child with autism's individual needs based on general guidelines (Autism Speaks, 2007). This program dates back to the 1960s when Doctor Eric Schopler, R. J. Reichler and Ms. Margaret Lansing were working with children with autism and constructed a means to gain control of the teaching setup so that independence could be promoted in the children (Autism Speaks, 2007). The TEACCH approach uses the environment to nurture physical and social interaction and to accommodate the difficulties a child with autism has while training them to perform in acceptable and appropriate ways. Dr. Goldstein (2006) explains that the children work in a highly structured environment which may

include physical organization of furniture, clearly delineated activity areas, picture-based schedules and work systems, and instructional clarity.

It is believed that the structure for autistic children provides a strong base and framework for learning. Building on the fact that children with autism are often visual learners, TEACCH brings visual clarity to the learning process in order to build receptiveness, understanding, organization, and independence (Autism Speaks, 2007). Although this approach does not specifically focus on social and communication skills as fully as other therapies, it can be used along with such therapies to make them more effective. This technique emphasizes the importance of sharing information between professionals and parents while acknowledging the expertise of the professional for skills training and the expertise of the parent about the child's own unique characteristics (Gresham, Beebe-Frankenberger, & MacMillan, 1999). A collaborative multidisciplinary approach is the most effective with this type of treatment.

Speech Therapy

Children with autism benefit differently from speech therapy depending on the intellectual and social development of the individual (Autism Speaks, 2007). Some autistic children may be unable to speak, whereas others have broad vocabularies and can speak at length on specific topics (Autism Speaks, 2007). Often children with autism have difficulty communicating in a socially appropriate manner, such as knowing what to say, how to say it, and when to say it in a social setting (Autism Speaks, 2007). Speech therapy teaches socially appropriate communication skills as well as pronunciation techniques.

Language development skills include joint attention including eye gaze and referential gestures such as pointing, showing, and giving, and social initiation such as questioning and talking (Autism Speaks, 2007). The goal of speech therapy is always to improve useful communication whether it is verbal or nonverbal. Although there is no one treatment that is found to improve communication in every child, the best treatment begins early in the preschool years and includes professionals and parents (Autism Speaks, 2007). For children with extreme difficulty communicating, gestured communication and symbols such as picture boards can be attempted to improve useful communication (Autism Speaks, 2007). The Picture Exchange Communication System is a form of speech therapy that enables an individual to communicate using pictures that represent ideas, activities, or items (Neurology Channel, 2007). This system enables the individual to convey requests, needs, and desires to others by simply handing them a picture or a series of pictures (Neurology Channel, 2007). It is extremely important with all interventions to have periodic evaluations to find the best approaches and to reestablish goals for the child (Autism Speaks, 2007).

Occupational Therapy

The goal of occupational therapy is to teach or improve skills that allow an individual to participate as independently as possible in life activities (Autism Speaks, 2007). Activities of daily living that are taught with occupational therapy include dressing, feeding, toileting, grooming, fine motor skills, visual skills, and social skills. Activities such as riding a bike or walking properly are also important skills for children

with autism to learn, which allow for their safe transportation within the community (Autism Speaks, 2007).

Each treatment therapy approach utilized to improve an autistic child's life is more beneficial with a collaborative effort from medical and educational professionals, as well as parents and other family members (Stahmer, Collings & Palinkas, 2005). With the learned skills needed to successfully function in everyday life, a person with autism can be successful in appropriate social interactions and play. This helps to improve the quality of life for an individual with autism.

Sensory Integration Therapy

Sensory integration is the process in which the brain interprets external stimuli such as movement, touch, smell, sight and sound (Autism Speaks, 2007). Children with autism often display symptoms of Sensory Integration Dysfunction, which makes it difficult for them to process sensory information from external stimuli (Stahmer, et al., 2005). Children can have mild, moderate or severe Sensory Integration Dysfunction deficits, which either appear as hypersensitivity, an increased sensitivity, or a hyposensitivity which is a decreased sensitivity to touch, sound and movement (Autism Speaks, 2007). The goal of sensory integration therapy is to enable the sensory system to process external stimuli input in a more typical way and when this therapy is successful, it can improve attention, concentration, listening, comprehension, balance, coordination, and impulsivity control in some children (Autism Speaks, 2005).

When using this therapy, a special program will be developed to provide sensory stimulation to a child to improve the process which the brain interprets sensory

information (Autism Speaks, 2006). These programs are developed by an occupational therapist and a physical therapist to enhance the child's ability to interpret external sensory stimuli (Autism Speaks, 2006).

Relationship Development Intervention

Based on the work of psychologist Steven Gutstein, Relationship Development Intervention focuses on developing relationships and improving the long-term quality of life for individuals with autism (Autism Speaks, 2007). The Relationship Development Intervention program is a parent-based treatment that addresses issues individuals with autism have of gaining friends, feeling empathy, expressing love, and having the ability to share experiences with others (Keeney, 2005).

The initial research surrounding the Relationship Development Intervention program indicates that 12 of the 17 children in the study group improved in at least one area of the Autism Diagnostic Observation Schedule, a standardized protocol for observation of social and communicative behaviors associated with autism (Keeney, 2005). Dr. Steven Gutstein, author of the study, challenges families and professionals to think beyond helpfulness and daily tasks as a successful outcome for individuals with autism, and strive for enhanced quality of life (Keeney, 2005). This intervention is still being studied with encouraging findings.

Alternative Treatments

There are many controversial alternative treatments for children with autism partly because there is no medical cure. Many parents pursue alternative approaches because of a desire to try almost anything that might help, including claims of

improvements from other families with autistic children (Blackwell & Niederhauser, 2003). Some, but not all, of the more popular alternative therapy treatments for autism include unconventional diets and vitamin supplementation (Blackwell & Niederhauser, 2003), and according to Gresham, et al. (1999), facilitated communication and auditory integration training are two common strategies for alternative treatments. Facilitated communication refers to a method of providing the physical support to a person who is unable to communicate by enabling the person to form words with letters or by pictures (Gresham, et al., 1999). This approach is similar to speech therapy, but bases its treatment on the hypothesis that all children with autism possess a sophisticated understanding of spoken and written language but cannot express themselves because of a motor deficit (Gresham, et al., 1999).

Auditory integration training is a method developed by Berard (1993) designed to soften spoken sound frequencies due to a hypo- or hypersensitivity of specific frequencies in children with autism (Gresham, et al., 1999). Auditory integration is based on the idea that children with autism are inhibited by hypersensitivity to auditory stimulation which leads to aggressive behavior (Gresham, et al., 1999). The goal of this therapeutic approach which integrates the softer frequencies into a child's schedule on a regular basis, is that the child will be less sensitive, and therefore be less affected by the sound frequencies.

Verbal Behavior Intervention

Verbal behavior intervention is seen as an addition to ABA and even though both are based on theories developed by Skinner, there are differences in concepts (Autism

Speaks, 2007). Jack Michael, PhD., Mark Sundberg, PhD., and James Partington, PhD., among others in the field, focused their research on B.F. Skinner's analysis of verbal behavior and its effectiveness of teaching language skills to improve ABA programs (Autism Web, 2010). This research has improved ABA programs by emphasizing the important elements in language acquisition and captures a child's motivation to develop a connection between the value of a word and the word itself (Autism Web, 2010). The verbal behavioral intervention focuses on teaching specific components of expressive language, therefore teaching a child that words are valuable and will assist them to getting their wants and needs (Autism Web, 2010).

Verbal behavior intervention puts an emphasis on the function of language rather than the form of which it is used (Autism Web, 2010). An example of using this intervention would be to first teach the child to ask for an item any way he/she can, that is, vocally, or using sign language or gestures, only when he/she actually wants that item. The child then captures the desire for that item and turns it into the lesson that the word, sign, or gesture will get the child what he/she wants (Autism Web, 2010). One of the initial ideas behind the verbal behavior treatment is to teach a child that words have functions and the child will receive what he/she wants with the use of the correct word (Autism Web, 2010). This approach is incorporated into the ABA treatment for children.

Applied Behavioral Analysis Background

According to Wallin (2007), applied behavioral analysis is a framework for the practice of a science, not a specific program. In most educational programs in which applied behavioral analysis is said to be used, individuals run a program based on discrete

trials, which are an element of applied behavioral analysis (Wallin, 2007). Wallin points out that there are many different terms being used for applied behavioral analysis-based interventions for children with autism, including a) Intensive Behavior Intervention, b) Applied Verbal Behavior, c) the UCLA model, d) Discrete-Trial Training, e) Natural Environment Training, and f) Pivotal Response Training. The various forms of applied behavioral analysis may focus on different target behaviors and have a unique system of instruction, but each is based on the science of applied behavioral analysis (Wallin, 2007).

Baer, Wolf, and Risely (1967) proposed seven important elements of an applied behavior analysis-based program:

1. The chosen behaviors must have some social significance in order for them to be applied; The program must be behavioral with environment and physical events recorded with accuracy;
2. The program must be analytic with clear evidence that the intervention is responsible for a change in a specific behavior;
3. The program must be technological with the techniques described completely allowing for a duplication of the intervention by another individual;
4. The program must be conceptually systematic with important accepted principles;
5. The program must be effective in changing the target behavior to a significant degree, and;
6. The program should have generality, with the change in behavior seen in a wide variety of environments.

These elements are a basic outline for the implementation of applied behavioral analysis.

Children with autism are slowly and purposefully taught how to learn with applied behavioral analysis. The most basic skills that most individuals learn naturally are broken down into pieces small enough for a child to understand and they are repeated over and over until they become part of the child's behavior (Autism Web, 2010). This basic behavior is built upon until the child begins to understand things individually (Autism Web, 2010). The general importance of ABA is teaching a child how to learn from the normal environment and how to act in ways that will consistently produce positive outcomes (Autism Web, 2010).

In order for ABA to work, there must be an understanding of how individuals with autism are stimulated by their environment, and the target behavior must be observable and measurable (Schreibman, 2000). When conducting the intervention, all data including frequency, positive and negative attempts, and the specific stimuli must be collected and recorded in order to measure the individual's change in behavior (Schoen, 2003).

Discrete Trial

A discrete trial is a teaching method for many behaviorally-based interventions used in teaching individuals with autism (Wallin, 2007). Discrete trial training is often used to aid with learning difficulties in areas of attention, motivation, stimulus control, generalization, communication, appropriate social situations, and cause-effect learning (NIMH, 2004). According to Wallin, a discrete trial is a single cycle of a behaviorally-based instructional routine which may be repeated several times in succession, several

times a day, over several days, or until the skill is mastered. There are four parts to a discrete trial training, which include a target stimulus, a prompt or a cue from the teacher, a response from the child, and a reinforcing stimulus (Wallin, 2007).

Many children with autism begin the discrete trial training with very minimal attention spans. Wallin (2007) explains that tasks are broken down into short, simple trials with the beginning interactions only being a few seconds in length. With the increase in the child's attention span, the lengths of the interactions increase appropriately (Wallin, 2007). Tangible and external reinforcements such as food, toys, sensory integration, and time to play are used with social praise to motivate the child to complete a task (NIMH, 2004). The fundamental ideas of short interactions and motivating techniques are used to shape wanted or unwanted behavior of children with autism.

Early Intervention

Hume, Bellini, and Pratt (2005) found early intervention to be a critical element of intervention plans for individuals with autism. Interventions that start before age 5 have notably improved outcomes in individuals with autism, as apposed to those whose interventions start at a later age (Hume, et al., 2005). Rogers (1996) found that early interventions appeared to reduce symptoms in young children with autism more quickly than interventions performed on older children.

Early intervention services are aimed at minimizing the impact of disabilities on the development of a child. Services such as applied behavioral analysis, speech and language instruction, occupational therapy, physical therapy, and psychological

evaluation are all included in an early intervention plan (Autism Speaks, 2007). Early intervention services may be directed either toward a child or an entire family. The services for families may include training to help the family reinforce or generalize their child's new skills, and counseling to help the family adapt to the changed circumstances associated with having a child with a disability.

The importance of early intervention and early childhood programs for individuals with autism have extensive support by researchers and advocates, with many questions remaining about the dose, intensity, mode of delivery, age of implementation, and intervention settings (Hume, et al., 2005). The tests implemented in diagnosing autism are continually being improved, assisting in early intervention techniques and outcomes.

Limitations of Applied Behavioral Analysis

The limitations of applied behavioral analysis interventions with individuals with autism are numerous (Schoen, 2003). Schoen explains that the format and delivery of applied behavioral analysis is extremely intense and intrusive for the recipient. The individual receiving the intervention should be carefully monitored for stressful reactions and traumatic experiences during implementation of applied behavioral analysis (Schoen, 2003).

Individuals may not generalize the learning and may only react to the stimuli in one environment (Schriebman, 2000). It is important to select natural environments for instruction to allow the skills learned to be extended into real world situations (Schoen, 2003). With a multidimensional outlook on the individual with autism, Schoen points out

that each individual has a spectrum of difficulties, range of abilities, age, culture of family, and characteristics of the individual, which suggest that one intervention may not be a sufficient treatment plan. The consistency of the intervention within the home and the learning environment is extremely important in the intervention process. Clearly, each treatment needs to be adapted to meet specific considerations for the individual (Schoen, 2003).

Chapter 3

METHODS

Introduction

This chapter explains the methodology of the research study as well as the selection of subjects, the procedures, and the protection of the rights of the participants. This is an exploratory study of parent and/or caregiver perceptions of the utilization of ABA with their children with autism. The data were gathered through interviewing research participants about the difficulties implementing ABA at home or in social environments on children with autism.

Design

The primary purpose of this study is to better understand the difficulties and successes of parents and/or caregivers with the implementation of ABA. The study is exploratory and uses qualitative methodologies. Parents and/or caregivers participated in a semi-structured interview regarding their experiences around their child's behavioral difficulties and the implementation of ABA.

Grounded theory operates on the premise that the theory emerges from the data and as a result is inductive, not deductive. This research does not strive to prove any hypothesis and looks for the conditions and consequences that relate to the core category (Strauss, 1997). Open-ended questions guided the data collection process. Grounded theory strives to find reoccurring themes or pattern among the data. Since core categories can have different kinds of appearances under different conditions, the researcher utilizes selective coding to find common themes within the data (Strauss, 1997).

Procedure

The study participants were a convenience sample of parents and/or caregivers whose child has a diagnosis of autism and who received educational services through the Yolo County Office of Education. Permission to conduct the study was obtained from Jim Coulter, the Director of Special Education at the Yolo County Office of Education. All participants were aware of their child's diagnosis of autism and were accustomed to discussing issues regarding their child's diagnosis and intervention plan. Information and consent forms were distributed in all autism programs in Yolo County (see Appendix A). Participants met the criterion of being a guardian and/or parent of a child, ranging from age of diagnosis to 21 years, with a diagnosis of autism (see Appendix C).

Those parents/caregivers who agreed to participate in the study were asked to sign a consent form and to provide a telephone number where they could be reached. The end result was four interviews including three interviews of mothers and one interview of a husband and wife. Interview questions were developed by the researcher for the parents/caregivers (see Appendix B). The interviews were conducted in convenient locations for the participants and were between 30 and 90 minutes in length. Interviews were taped, professionally transcribed, and analyzed for common themes/concerns.

Data Analysis

Qualitative research seeks to draw meaning from direct observations. This methodology focuses on providing description, explanation, and evaluation. The primary focus is on understanding people involved in the data collection. In this study, parents and/or caregivers were interviewed to better understand their difficulties and any

modifications they made to ABA in their home and then analyzed for common themes. In most qualitative studies data collection, data analysis, and drawing conclusions all occur simultaneously and in the context of one another.

Protection of Human Subjects

Participation in the study was voluntary. All participants' personal information and responses to the questions were kept confidential. Participants' names and names of their children have been changed for confidentiality purposes. The children are referred to as "minor" or "child" and parents/caregivers are referred to as "caregiver" or "parent" when being discussed in the findings. Access to all data, including tapes, was restricted to the researcher. Any identifying information was re-identified during transcription and the tapes were destroyed immediately after transcription. Also, all data collected for the study were destroyed after research was completed. To further protect the child and parents/caregiver's confidentiality, only the researcher knew the names of the children affiliated with this study.

This study was found to be "minimal risk." A "Request for Review by the Committee for the Protection of Human Subjects" was submitted and approved by California State University, Sacramento.

Chapter 4

FINDINGS

Introduction

In this chapter the researcher begins with a description of each parent/caregiver who was a participant in the study. As discussed in chapter 3, the interviews were transcribed and then analyzed for common themes. Four main themes were identified.

These themes include:

1. The issues and difficulties parents/caregivers have with dedicating themselves to ABA treatment;
2. Modifications parents/caregivers make in their lives in order to utilize techniques of ABA;
3. The impact the utilization of ABA has on relationships and roles in the family and community; and,
4. The various alternative treatments for children with autism utilized by parents/caregivers.

Participants

Four parents/caregivers were interviewed regarding their difficulties and successes with implementing applied behavioral analysis in their home with their autistic child. Three interviews were conducted with the mother of the autistic child, and one interview included the mother and father together.

Parent Number One

Lisa is a 38-year-old African American woman. Her son James is six years old. James was diagnosed with autism at the age of 3½. James's autism ranges between moderate to severe on the spectrum. Lisa and her husband, Tony, have been using applied behavioral analysis for 2½ years.

Parent Number Two

Heather is a 43-year-old Caucasian woman. She has a 10-year-old son, Ted, who is autistic. Ted was diagnosed with mild autism when he was almost three years old. Ted is a triplet with two sisters. Heather and her husband, Tom, have been using applied behavioral analysis for two years.

Parent Number Three

Ria is a 45-year-old Afghani woman. Her son Ben is ten years old. Ben was diagnosed with autism at 2½ years. Ben's autism ranges between moderate to severe on the spectrum. Ria and her husband, Thomas, have been using applied behavioral analysis for 2½ years.

Parent Number Four

Kelly is a 40-year-old Caucasian woman. She has a 12-year-old son, Josh, who is autistic. Josh was diagnosed with mild autism when he was seven years old. However, when Josh was 3½ years old, he was given multiple diagnoses, including Attention Deficit Hyperactivity Disorder, and Emotional Disturbance Not Otherwise Specified, with speech and language delays. Josh has high functioning autism; therefore Kelly and

her husband, Jack, have not solely utilized ABA. Kelly reports she has used different techniques of ABA along with other treatment approaches.

Emerging Themes

The main theme that emerged in all four interviews was the difficulty parents/caregivers have in applying ABA techniques consistently with both parents in the home. For example, Lisa and Tony struggled with different parenting philosophies that posed difficulty for the consistency and follow through of the techniques of ABA, with Lisa being much more structured in her parenting approach than Tony. Heather and Tom gave examples of personal characteristics which weakened consistency in their home, with Tom having a more lackadaisical personality, therefore having less consistency with data collection and behavioral techniques.

Lisa expressed difficulties implementing ABA in her home with her husband, Tony, stating “I think for me the biggest struggle was different parenting philosophies and how to take techniques and make them work in our home” (Lisa interview, July 9, 2007). It appears the implementation of ABA treatment in homes is demanding on parents and they find it difficult to fit the treatment into their daily lives. Different parenting philosophies, as Lisa has expressed, pose conflict in families regardless of having children with special needs; however, for Lisa and Tony the differences become more apparent with their child, James. He is their second child and Lisa reported having fewer parental disagreements with Tony when discussing how to raise their oldest, typically developing child.

Each parent's dedication to the implementation of ABA influences the consistency of techniques in a daily home environment. Lisa explained that it is frustrating for her when her husband does not follow the behavioral plan and techniques. In addition to her husband having difficulties with ABA, Lisa's friends and family members do not completely understand the treatment, and tend to give their opinions and advice on how to raise James. Lisa believes that the general public does not understand the dedication, patience, and change in lifestyle it takes to raise a child with special needs. "He's different, so we can't use what you would consider a traditional reasoning with a 3 year old who's autistic" (Lisa interview, July 9, 2007). Even though Lisa has attempted to change her parenting style, she and her husband continue to face difficulties with the consistency of implementing ABA in their home. Every day poses a different issue, so Lisa and her family are frequently forced to change and adapt to the environment and James' behaviors.

Heather found it difficult to be consistent with ABA techniques with her son, Ted, because there are multiple children in the home. Heather explained following the suggestions of the behaviorist was extremely difficult with three children the same age.

We have behaviorists come to the house and we did try to implement it. It's just hard when you're living with other kids and you have a house that you're trying to run and you're trying to use the token system. That's what seemed a lot to do.

(Heather interview, June 30, 2008)

Heather believes she and Tom were not disciplined enough to be thorough and consistent with the treatment. They both work full time jobs during the day and are at home with the

children in the evening. As with many two working parent households, these parents are tired and inconsistent with their children in the evening. This may be why Heather feels she is not disciplined enough to fully implement the treatment techniques at home. With having triplets, Heather and Tom must divide their attention between all three children, making it almost impossible to focus their full attention on the treatment approaches suggested by the behaviorists. Not surprisingly, the stress of both parents working full time seems to add to the inconsistency of the techniques of ABA in the home environment.

Difficulty and consistency with techniques are also influenced by an individual's personality. Heather describes her husband, Tom as being laid back and relaxed with the children. Keeping the data regarding antecedents, triggers, behaviors, and outcomes and/or consequences was difficult for Tom. Heather reported, "Things would happen in one room and the data sheets were in the other side of the house, so it just never seemed to flow" (Heather interview, June 30, 2008).

Being new to the treatment and not remembering all the information the behaviorist explained made implementation less easy for Heather and Tom. Heather reports,

I think that's probably the big thing is it's new and foreign and trying to deal with the everyday living of when he would have tantrums and try to remain calm and then try to remember every single thing the behaviorist told us. That was hard to put into place. (Heather interview, June 30, 2008)

If an individual has a relaxed, laid back personality, it makes the consistency and rigidity of data collection difficult. Tom preferred to enjoy his time with the children in the evening when the family was together; and therefore chose not to follow the techniques fully.

When both parents have careers outside their home, stress is added to the daily chores and routines of home life, especially for parents of children with autism. This was the case for Kelly and Tom. Even though Kelly's family did not strictly utilize ABA therapy with her son, Josh, she was able to give a different viewpoint with consistency and repetition in the home. Kelly and Jack both worked full time jobs and were unable to be home when Josh arrived home from school. According to Kelly, "We tried to put him in daycare...it was in the third grade. We finished out the year, and it didn't go well" (Kelly interview, May 23, 2008). The daycare was not successful for Josh because the staff was not familiar with ABA. Many times, due to the behaviors he exhibited, Josh would be sent home from school or daycare and a parent needed to collect him. Leaving during the day made it difficult for Jake to keep his job, therefore he resigned. Kelly reported that Jake quit his job to stay home to care for Josh, which in turn changed their lifestyle and family dynamics.

According to the specific techniques of ABA, consistency is key to the success of the child. This means both parents must be equally dedicated to the repetition and consistency needed to successfully implement the techniques of treatment in the home environment. In addition to consistency with different parenting styles, daily life posed an added stress on parental relationships. Lisa felt the stress of family expectations with

her son, James. She reports “having to distance yourself from the traditions of growing up” (Lisa interview, July 9, 2007), which in turn has influenced the implementation of ABA. Family expectations are learned throughout childhood into adulthood. Each family has its traditions and has developed ideologies. Lisa is a good example of a parent who has modified her personal beliefs and ideologies to raise a child with autism, and attempt to implement an intense behavioral treatment into daily life.

Families are impacted differently with family expectations, different parenting styles, and two working parent households. Each parent gave an example of the impact having a child with autism has had on their family, such as beliefs and childhood family traditions changed, a change in income and employment to consistently care for their child with autism, and family dynamics changed with members taking on additional roles to compensate for those not being completed by the autistic member of the family.

Another theme that emerged was how families modified ABA to fit into their daily life. Service providers often ask parents/caregivers to journal behaviors and data collection, which are an important aspect of understanding a child’s behaviors. Parents were asked by behaviorists to journal specific details of triggers, antecedents, the behavior, and outcome and/or consequence of each problematic behavior, including the time and date of the incident. At times, autistic children have patterns with unwanted behaviors and the data collection assists in finding such patterns. With the data collected, the patterns of behavior can be understood and modified with a plan of action for each specific situation. Varying environments also make data collection difficult for families due to the unpredictability of their child’s behaviors. For example, if a child exhibits

unwanted behavior in a social setting, service providers request the parent/caregiver document and collect the data surrounding the behaviors at the time of the incident. The unpredictability and variation of each situation makes data collection difficult for many individuals, which results in the modification of the data collection to meet the needs of the parent/caregiver collecting the data.

A modification was introduced by Tony (Lisa interview, July 9, 2007). He found it difficult to remember a pen and paper when going to the grocery store or to the park with James. Lisa reported data collection was easy for her because it was comfortable for her to carry around a journal and pen in her purse; however, her husband was not someone who was willing to carry around the needed materials. Tony and Lisa modified the data collection by utilizing cell phones. Tony would leave a message on their home voicemail regarding details of James's behaviors, therefore being able to document all the needed data for a behavioral incident at a later time. This enabled Lisa and Tony to document each incident and give the data to the behaviorist to analyze.

Each family and/or caregiver may modify various ABA techniques to assist in the success of ABA treatment in the home environment. It is important to remember that each person learns differently and is successful in various activities throughout life due to adaptation and modification to fit his/her needs. Parents/caregivers must adapt the techniques learned from educators and service providers to have success with ABA in various environments including the home.

In addition to adapting and modifying ABA for each individual's learning styles and needs, various home environments present different problems individual to each

family and child. Heather's family and home environment are a strong example of the need to modify behavioral techniques. With autism, each individual has varying severity of features related to his/her diagnosis. For example, on one end of the spectrum, an individual may be very high functioning, independent and verbal, and at the other end of the spectrum, an individual may be non-verbal and not have the ability to function successfully without assistance. Ted is an example of a high functioning verbal child with autism and his parents needed to modify the planned ignore technique with him due to his ability to verbalize his wants. Heather explained due to Ted's ability to communicate, when she ignores his repetitive question, he would ask the same question in several other ways to retrieve an answer. Heather must be able to deflect each question form if she planned to ignore Ted's obsessive thought process, which she explained was difficult when she was tired. She reports,

The planned ignoring was also really, really difficult for us to do because he's verbal so he'll just get in your face and just keep asking the same question over and over again until you answer him, and he'll ask it five different ways to get you to respond to him. (Heather interview, June 30, 2008)

Heather, having triplets in the home, found it difficult to implement the techniques when all three children were in the room. "It was just difficult to implement at home with both of us working" (Interview 2, June 30, 2008), and having multiple children who wanted attention. Heather and Tom attempted to utilize the technique of planned ignoring, but found it difficult due to Ted's verbal ability. Heather explained the

techniques worked great at school, “but at home it just didn’t seem to work very well. We just weren’t disciplined enough, either” (Heather interview, June 30, 2008).

Another technique Heather noted as a creative modification at home with Ted was the visual schedule. Even though Ted no longer utilized his daily schedule in the home, at times, when there are unique events occurring, Heather would use visual aides to prepare Ted for the event. For example, Ted was going to summer camp the following week, so as soon as Heather knew he was accepted into the summer camp, they started talking about the camp. Heather and Ted had talked about him going to summer camp for approximately 3 months prior to the summer camp. “So if I know something big is coming up, as soon as I know that we’re doing it, I’ll start prepping him for it, just talking about it, telling him what to expect” (Heather interview, June 30, 2008). Heather explained she utilized the internet to show Ted the Easter Seals website and pictures of the camp. This enabled Ted to see where he would be and lessened his anxiety. Heather read many portions of the website to Ted including the different activities and “daily blog, so I could actually go through the day and say, this is what you’re going to do, and this is what you’re going to do...” (Heather interview, June 30, 2008). Heather noted this was the first time Ted was going away overnight, and the camp was a week long.

Impact on Family Relations

During the interviews, it was evident that family relations were impacted in homes with an autistic child. The author did not explore the impact of family relations in detail, however, it was apparent that raising a child with autism does change family roles. For example, family members may be given more responsibilities and chores to assist

with those not completed by the autistic child; there may be a change in lifestyle, such as parents having fewer social outings and employment difficulty due to child care needs; and there may be a change in the parental relationship with tension and stress of parenting a child with autism. The researcher was not successful at asking further questions regarding difficulties the study participants have in their marital relationships during the interviews, therefore this is a topic/theme that should be further analyzed.

Alternative Treatments

Parents/caregivers often use alternative treatments in addition to ABA to reduce the common symptoms of autism. Due to the fact that autism can not be cured, parents/caregivers try alternative treatments in order to improve their child's quality of life. Examples of alternative treatments include sensory integration, speech therapy, and prescription medication, among others. Each alternative treatment involves differing beliefs, opinions, and experiences of the child and parents/caregivers.

Sensory Integration

The utilization of sensory integration simultaneously with ABA is very commonly seen in autism programs in the public schools. Sensory integration is used to calm or excite a sense in the body. For example, to stimulate the equilibrium a child may have a regimen of swinging for 15 minutes after every 30 minutes of one-on-one instruction. Some children with autism are calmed by the movement of a swing, while others are excited and overwhelmed. Another example of sensory integration is the stimulation of the tactile senses, by playing with shaving cream on a table or by putting a child's hands and/or feet into a bucket of beans. This may be accepted by some children to various

degrees or rejected completely by others. No individual is equally affected by sensory therapy and may use varying degrees of the treatment.

Kelly reported “it was all sensory” for Jack as he was “seeking input for the vestibular system in a way that’s totally not conducive to a classroom” (Kelly interview, May 23, 2008). Jack needed physical stimulation to get his body into a normal state, which allowed him the ability to learn. Kelly went on to explain that at home, Jack “was not able to calm his body to go to sleep” (Kelly interview, May 23, 2008) at times without being swaddled tightly. Other children with autism may be calmed by a heavy blanket or rhythmic humming. Each day is different for Jack, and techniques utilized to excite his sensory system that worked yesterday may not work the same today.

It is common to see children with autism seeking out sensory stimulation with the repetitive motions or behavioral patterns, such as flicking his/her fingers in front of his/her eyes for visual stimulation, or rocking front to back for the stimulation of the equilibrium. Kelly explained that Jack “definitely seeks it on his own” and is able to know what his body needs for comfort. Jack has difficulty generalizing his sensory integration “into his everyday environment” and he is “not totally able to do it” without direction. However, over time the sensory integration taught Jack the cues of his body and “overall the sensory needs have improved” as he has grown. Children in the public school system often have an Individual Educational Plan (IEP) which enables the child to have sensory integration throughout the day and/or week depending on the specific child’s needs.

Sensory integration is a wide field which entails much more stimulation, regimented routine, and various techniques of stimulation specific to each child than discussed in this research. This study simply touched on the topic of sensory integration and did not go into detail. In addition, other alternative treatments were not addressed during the interviews as therapies utilized simultaneously with ABA. However, this area should be explored more for understanding all treatment approaches used by parents/caregivers to reduce the child's autistic behaviors and features.

Summary

This research study revealed all the families interviewed modified various ABA techniques for the treatment to be successful in their home. Family roles and parental relationships were affected by the changes, which then interfered with daily activities and parental obligations. The importance for parents/caregivers to collaborate and offer suggestions to others for the increased success of each behavioral technique became evident through out the study. Social networking and shared experiences are important for positive outcomes with ABA.

Chapter 5

CONCLUSION

In 2007, the U.S. Department of Education reported autism was on the rise and growing at the startling rate of 10-17% per year. According to the Centers for Disease Control and Prevention (CDC, 2010), in 2010, an estimated 1 in 110 children in the United States have an Autism Spectrum Disorder and autism now accounts for 45% of all developmental disabilities within California (National Autistic Society, 2007). The statistics indicate autism is more common than childhood cancer.

Although there has been multiple hypotheses including biological, environmental and genetic factors for the cause of autism, there is no known cause or cure. Treatment for these children often takes a multidisciplinary approach and includes educational instructors, medical professionals, and parents'/caregivers' observations. Even though there is no cure for autism, there are many treatment approaches in which children with autism learn more independence and communication skills, including sensory integration theories, speech therapy, occupational therapy, relationship development intervention and verbal behavioral analysis. There is no single treatment protocol for all children with autism due to the features of autism being presented in each individual differently; however, most professionals agree that early intervention is important (NIMH, 2004).

The main purpose of the research was to better understand the difficulties and successes parents and/or caregivers have with the implementation of ABA with their autistic child. The researcher focused her study on ABA, which is an intensive therapy

for individuals with autism that involves instruction directed by adults in a highly structured fashion. The researcher hoped that interviews of parents/caregivers regarding the implementation of ABA in their home environment would introduce ideas and assist other parents/caregivers in implementing ABA in an effective manner.

The study was qualitative and included interviews with four parents/caretakers of children with autism. The sample size was small due to the lack of willingness of parents/caregivers to participate. Five individuals came forward to be interviewed from all classrooms in Yolo County with autistic children. One parent/caregiver initially gave contact information, and despite an active attempt by the author to schedule an interview, the individual did not return the contact. Therefore, the end result was four interviews.

In addition to the small sample size, the study size did not allow for a large diversity in cultures, languages, and family structure. All of the individuals interviewed were married heterosexual females with multiple children. The author is monolingual and was not able to interview individuals who did not feel comfortable having a discussion in English. The small number of parents who volunteered to participate may be due to the possibility that parents from other cultures may not fully understand or accept the diagnosis of autism. Alternatively, it may be difficult for them to communicate openly with service providers. Also, parents from other cultures may have social standards which prohibit them from discussing their autistic child, or expressing their frustrations regarding a behavioral treatment that was not successful for them or proved difficult to implement in their home. The author speculates there may be a sense of

shame or embarrassment by individuals who have difficulty or are unsuccessful with the implementation of ABA in the home environment.

The main theme that was identified from the interviews was the dedication and follow through demanded of these parents. Having a child with autism was described as being extremely difficult and demanding. These families explained being overwhelmed by the pressures of implementing a behavioral treatment plan, in addition to the demands and stress of multiple children, employment, finances, day care, personal relationships and social influences. For example, dual working parent households have the additional stress of finding a day care provider who is able to handle the needs of an autistic child, including all unwanted behaviors. Another example is the difficulties an autistic child may present when socializing at a community park or a friend's home. These stresses also create financial worries and social frustrations.

The study participants gave examples of how their home and family were modified and adjusted in order to implement ABA. Modifications were made in their home and family as well as with specific ABA techniques, enabling the treatment plan to be utilized more effectively. For example, siblings took on more responsibilities and chores in the home to compensate for tasks not done by the autistic child. A study participant also described utilizing small parts of a technique such as ignoring unwanted behaviors, which proved difficult with triplets. With each child and family being significantly different from another, the interviewers discussed modifications specifically used in their home. For example, one interviewee described utilizing technology to track behavioral triggers and outcomes by calling the home phone and leaving a message with

the important information. This enabled the parent to document the information at a later time, and not worry about documenting the behavior with paper and pen at the time of the incident. The interviewee explained this allowed for more flexibility and seemed to work well for her husband.

Even with the modifications to various ABA techniques, these parents continued to have difficulties with their commitment to the treatment. Although the consequences resulting from the lack of follow through and dedication for the parents/caregivers was the continuance of an unwanted behavior, by the end of the day parents/caregivers are too exhausted from other pressures in daily life to complete the tasks requested of them by the service providers.

Due to the intensity of ABA, this treatment is difficult to implement in its entirety in a general environment and it appears from these interviews that traditional ABA may be essentially impossible to implement in an average two parent household. The behavioral techniques were designed to be implemented in an institutionalized and very controlled environment and the interviews indicate that consistency is difficult in an uncontrolled environment. The author believes social networking and discussions between parents are important to create support and commonality. Brainstorming ideas with service providers and other parents/caregivers of children with autism regarding modifications may produce new ideas and potentially enable parents to implement ABA more effectively.

Another theme identified was the difficulties autism and ABA treatment added to the study participant's personal relationships. In dual parent households, it is important

that both parents/caregivers have similar ideas or interests in the dedication and follow through of the techniques for there to be a positive outcome in the home. It is clear from the interviews that, at times, both parents did not have the same enthusiasm or energy to complete the tasks required of them. This seemed to result in creating a rift in their marital relationship. This lack of consistency or agreement from both parents was sometimes related to a) differing personality traits, for example, having high energy as apposed to being lackadaisical; b) parenting styles, for example, being strict rather than lenient; and c) health, including the amount of sleep both parents are able to have. On at least two occasions, the author failed to pick up on cues reported by the parent/caregiver relating to how parenting an autistic child created tension in their marital relationship. This could have been an important theme had the author explored this issue further. Unfortunately, the author did not address this issue in any detail or ask follow up questions regarding what kinds of problems were created in their marital relationship. Future studies should explore this area further.

Other ideas for future research include broadening the sample group to include parents/caregivers of children with multiple disabilities. The CDC reports autism occurs more often in people who have certain medical conditions, and 10% of children with an autism spectrum disorder have an identifiable genetic disorder, such as Fragile X Syndrome, Down Syndrome, and other chromosomal disorders (CDC, 2010). One study participant reported her child had multiple disabilities including Attention Deficit Hyperactivity Disorder and speech delays. Including parents/caregivers of children with multiple diagnoses would potentially provide a better understanding of the use of ABA

and alternative treatments. The interviews addressed alternative treatments including sensory integration and occupational therapy in the educational setting, however, alternative treatments were not discussed in detail regarding the home environment.

In addition to multiple diagnoses, the age of the child when he/she was diagnosed, and the age he/she received his/her first intervention treatment are also factors which could change the outcome of the behavioral treatments. The parents/caregivers interviewed reported their autistic children were diagnosed on average at age three, and had utilized ABA techniques in their home on average of two years. It is hoped that with the rise of autism diagnosis, children are receiving treatments and intervention services at an earlier age, therefore contributing to the behavioral changes. The early intervention services could add to the effectiveness of ABA utilized by parents/caregivers. Additional research with these varying factors could be beneficial to service providers, possibly changing the assistance they are able to give parents/caregivers.

The findings of this study are important in assisting parents/caregivers in realizing they are not alone when lacking the consistency required of ABA. It is hoped this study will assist service providers in understanding the demands and pressures parents/caregivers have in regard to personal strength, dedication, modifications, and competency of this treatment approach. As one study participant stated, "I think the biggest struggle was how to take these techniques and make them work in our home."

APPENDICES

APPENDIX A

Parental Consent Form

April 6, 2007

Dear Parents/Guardian:

My name is Jillian Reimers and I am currently a graduate student in the Social Work program at California State University, Sacramento. **At this time, I am conducting research to better understand caregivers' perceptions of implementing Applied Behavioral Analysis, a behavioral treatment program for their children diagnosed with Autism.** Although you will not directly benefit from participation in research, your responses will help me and others better understand the benefits and difficulties in the behavioral treatment of Applied Behavioral Analysis.

The study consists of an interview in which I will ask a series of open ended questions. The interview will take approximately 45 minutes. It is hoped that your responses will assist in understanding the implementation of Applied Behavioral Analysis.

Your participation in this study is entirely voluntary. If you volunteer to be in this study, you may withdraw at any time without consequences. Since these interviews may be tape recorded, there is a possibility that you may experience some nervousness. Should this occur the researcher will turn off the tape recorder. You may also decline to have the interview tape recorded. Although not anticipated, you may decline to answer any questions that cause discomfort.

Your personal information and all responses given will be kept confidential, and will only be used in assisting the research for my thesis project. No one other than the researcher will have access to your information.

If you have any questions regarding this research, please feel free to contact Jillian Reimers at (530) 219-3408 or by email at: jillianreimers@hotmail.com.

Your signature below indicates that you have read this page and agree to participate in the research.

Your Signature

Date

Phone number

Best times when you can be reached

Please return consent form by April 30, 2007

APPENDIX B

Interview Questions

1. What was your reaction when you were first introduced to Applied Behavioral Analysis?
2. What were the most difficult parts of implementing Applied Behavioral Analysis for you when you first used this approach with your child?
3. Were there certain aspects of this approach that you felt uncomfortable with? What were they and how did you resolve these?
4. What has been the most positive aspect of this approach for you?
5. DO you feel Applied Behavioral Analysis has been beneficial and effective for you and your child?
6. What changes or modifications of Applied Behavioral Analysis have you found beneficial with your child? How were these modifications learned?
7. Please describe your implementation of Applied Behavioral Analysis with your child. How has the treatment evolved with use?

APPENDIX C

Demographics of Study Participants

Parent's/Caregiver's age: _____

Race: _____

Highest Education Achieved: _____

Age of Child with Autism: _____

Age of Child When Diagnosed with Autism: _____

How Long Using Applied Behavioral Analysis: _____

REFERENCES

- Autism and PDD Support Network. (2006). *Using the TEACCH for autism treatment*. Retrieved from <http://www.autism-pdd.net/teacch.html>
- Autism Society. (2006). *Improving the lives of all affected by autism: Facts and stats*. Retrieved from http://www.autism-society.org/site/PageSaver?pagename=about_what_is_factsstats
- Autism Society of America. (2007). *Defining autism*. Retrieved January 10, 2007, from <http://www.autism-society.org/site/pageserver>
- Autism Speaks. (2007). *Be informed: Need to know*. Retrieved February 15, 2007, from http://www.autismspeaks.org/be_informed.php
- Autism Web. (2010). *A parent's guide to autism and PDD*. Retrieved July 15, 2010, from <http://www.autismweb.com/index.htm>
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some current dimensions of applied behavior analysis. *Journal of Applied Behavioral Analysis, 20*, 313-327.
- Berard, G. (1993). *Hearing equals behavior*. New Canaan, CT: Keats.
- Blackwell, J., Niederhaser, C. (2003). Diagnose and manage autistic children. *Nurse Practitioner, 28*(6), 36.
- Centers for Disease Control and Prevention (CDC). (2007). *Facts about ASDs*. Retrieved from <http://www.cdc.gov/ncbddd/autism/facts.html>
- Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publications Company.
- Greene, R. R. (1999). *Human behavior theory and social work practice* (2nd ed.). New York: Aldine de Gruyer.
- Gresham, F. M., Beebe-Frankenberger, M. E., & MacMillan, D. L. (1999). A selective review of treatments for children with autism: Description and methodological considerations. *School Psychology Review, 28*(4), 559-575.
- Hume, K., Bellini, S., & Pratt, C. (2005). *The usage and perceived outcomes of early intervention and early childhood programs for young children with Autism spectrum disorder*. Bloomington, IN: Indiana University Press.

- Keeney, D. (2005). *Autistic children benefit greatly from relationship development intervention program*. Retrieved from <http://www.medicalnewstoday.com/articles/23153.php>
- National Autistic Society. (2007). *Applied behavioral analysis*. Retrieved from <http://www.autism.org.uk/en-gb/living-with-autism/approaches-therapies-and-interventions/behavioural-interventions/applied-behavioural-analysis.aspx>
- National Institute of Mental Health (NIMH). (2004). *Autism spectrum disorders: Pervasive developmental disorders*. Retrieved from <http://www.nimh.nih.gov/publicat/autism.cfm>
- National Institute of Neurological Disorders and Stroke (NINDS). (2005). *Autism fact sheet*. Retrieved January 10, 2007, from <http://www.ninds.nih.gov/disorders/autism/autism.htm>
- Neurology Channel. (2007). *Autism*. Retrieved February 2, 2007 from <http://www.neurologychannel.com>
- Rogers, S. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders*, 26, 246-246.
- Rosenwasser, B. & Axelrod, S. (2002). More contributions of applied behavior analysis to the education of people with autism. *Behavior Modification*, 26(1), 3-8.
- Rubin, A. & Babbie, E. R. (2005). *Research methods for social workers* (5th ed.). Australia, Canada: Brooks/Cole.
- Schoen, A. A. (2003). What potential does the applied behavioral analysis approach have for the treatment of children and youth with Autism? *Journal of Instructional Psychology*, 30(2), 125-130.
- Schriebman, L. (2000). Intensive behavioral/psycho educational treatments for autism: Research needs and future directions. *Journal of Autism and Developmental*, 30(5), 373-377.
- Stahmer, A. C., Collings, N. M., & Palinkas, L. A. (2005). Early intervention practices for children with Autism: Descriptions from community providers. *Focus on Autism & Other Developmental Disabilities*, 20(2), 66-79.
- Strauss, A. L. (1997). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.

Strauss, A. L. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.

Wallin, J. M. (2007). *Teaching children with autism*. Retrieved from <http://www.polyxo.com/discretetrial/>