

The Experiences of "Autism Mothers" who become Behavior Analysts: A Qualitative Study

Mary Lynch Barbera

Abstract

Over the past 15 years there has been a dramatic increase in the incidence of autism. At the same time, the number of professionals qualified to coordinate effective behavioral interventions has been limited and often prohibitively expensive. No one understands this better than parents of children with autism. For these and other reasons, some of these parents have chosen to complete the requirements leading to certification in applied behavior analysis. This paper describes a pilot study into the backgrounds and experiences of six such "autism mothers." The study utilized qualitative research methods to explore the participants' transition from the role of mother to the additional role of ABA professional. Also explored were the participants' perceptions regarding both sides of the parent-professional partnership and their recommendations for training parents of newly diagnosed children with autism.

Keywords: autism, mothers, parents, experts, parent training, Board Certified Behavior Analyst (BCBA)

Introduction

Over the past 15 years there has been a dramatic increase in the diagnosis of autism. At the same time, the number of professionals qualified to coordinate intensive behavioral intervention programs has been limited and often prohibitively expensive. For a variety of reasons, including the desire to address the growing need of qualified professions, some parents of children with autism have chosen to enter the field of applied behavior analysis (ABA) as professionals. To do so, they have completed coursework and supervised practicum experiences leading to the credential known as Board Certified Behavior Analyst (BCBA). This paper describes a pilot study into the backgrounds and experiences of six such "autism mothers" who pursued this course. Qualitative research methods were used to explore the participants' transition from the role of mother to the additional role of ABA professional. Also explored were the participants' perceptions regarding both sides of the parent-professional partnership and their recommendations for training other parents of newly diagnosed children with autism. To place this study in context, it is helpful to review some key issues regarding the role of parents in the history of autism, in the search for autism treatments, and in the process of intervention. It is also helpful to consider the experience of parents living with autism more generally. A consideration of these issues will be followed by a description of the methods and a summary of the results.

Parents Defining the History of Autism

The term "autism" was first identified in 1943 by Dr. Leo Kanner, a pediatric psychiatrist at Johns Hopkins Hospital. At about the same time, Hans Asperger, an Austrian pediatrician described a similar albeit milder form of the disorder now known as Asperger's Syndrome. During this post-war era, the field of psychology was dominated by psychoanalysis, so autism was quickly deemed a psychoanalytic disorder and its cause, according to Bruno Bettelheim, was presumed to be the lack of love that cold, and demanding "refrigerator mothers" accorded to their children (Carmichael, 2006).

Bettelheim's theory began to crumble in the 1960s owing to the work of a psychologist by the name of Bernard Rimland. Dr. Rimland became interested in autism when his own son began to present with symptoms of the disorder and when it became clear that the psychoanalytical framework could neither explain nor treat his son's condition (Rimland, 1964). Rimland knew that his wife did not behave in a cold and uncaring manner towards their son, and after an extensive review of the existing literature, he began to view autism as a neurologically-based developmental disorder. In 1964 Rimland published his ideas in a book called *Infantile Autism*, and in 1965 he founded the Autism Society of America. From this point on, parents began to classify autism as a neurologically-based disorder and by the early 1970's most professionals stopped blaming mothers for their children's diagnosis. However, autism was not recognized as a unique clinical diagnosis, separate from childhood schizophrenia or mental retardation, until the 1980s (Kantrowitz & Scelfo, 2006).

Over the past 15 years, an awareness of autism in our culture at large has been heightened by the dramatic increase in the incidence. Currently, one in every 150 American children is being identified with the diagnosis. Among the school-aged population in Pennsylvania, for instance, the number of students diagnosed with autism rose from 346 in 1993 to 5,805 in 2003. This is a 1578% increase over a 10 year period, and it is very close to the 1055% rate of increase reported by the U.S. National Department of Education (Wilson, 2006). Based on these figure, it can be argued that the United States is in the middle of an autism epidemic.

Given the growing incidence of autism and of the profound ways in which an autism diagnosis changes the lives of families, parents have once again taken a leadership role in the search for a cure. This was recognized by Dr. Thomas Insel, Director of the National Institute of Mental Health. In a recent cover story of Newsweek, Insel noted that, "Even longtime autism researchers say families have really led the way...families have become the real experts on this disorder" (Kantrowitz & Scelfo, 2006).

Parents as Advocates for Applied Behavior Analysis

While there is no cure for autism at this time, there are hundreds of treatments. However, the only treatment with scientifically validated support is applied behavior analysis (ABA) (New York State Department of Health, Early Intervention Program, 1999). In fact, ABA is the treatment recommended by the U.S. Surgeon General (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; United States Surgeon General, 2000).

Cooper, Heron, and Heward (2007) define ABA as "... a scientific approach for discovering environmental variables that reliably influence socially significant behavior and for developing a technology of behavior change that takes practical advantage of those discoveries" (p. 3). ABA offers scientifically-supported methods for increasing positive behaviors such (e.g., language, self help skills) and for reducing problem behavior (e.g., tantrums).

The power of ABA to improve the lives of children with autism was brought to the forefront by the work of Catherine Maurice, mother of two children with the diagnosis. In the late 1980's and early 1990's, Maurice provided her then-newly diagnosed toddlers with intensive behavioral intervention, and both children "recovered" from the disorder. The children's diagnosis, treatment, and recovery have been documented extensively both in professional journals (e.g., Perry, Cohen, & DeCarlo, 1995) and in a book written by Maurice (1993) called *Let Me Hear Your Voice*. Later, Maurice partnered with colleagues from within the professional ABA community to edit a book called *Behavioral Intervention for Young Children with Autism* (Maurice, Green, and Luce, 1996), which provided additional important information about intensive behavioral intervention. Largely due to the work of Maurice, parents of

children with autism in the mid to late 1990's and 2000's were given hope and direction for pursuing an effective approach to treatment. By reading Maurice books, parents learned that intensive early behavioral intervention could yield tremendous results.

The treatment that was provided to Maurice's children was based on the groundbreaking work of Ivaar Lovaas, a behavioral psychologist at UCLA. In 1987, Lovaas published a study describing the developmental progress of 59 children with autism (Lovaas, 1987). All children received some type of treatment. However, the 19 children who received 40 or more hours a week of 1:1 behavioral intervention demonstrated the best developmental outcomes. Moreover, nearly half (47%) of these children appeared "indistinguishable" from their same-age typical peers by first grade, and a follow-up study reported that they had continued to progress normally by the age of 13 years (McEachin, Smith & Lovaas, 1993). They all participated in their classes independently, without the need of aides or other special education services.

Since these early studies, research into the efficacy of ABA has continued. A generation of children has now grown up with the support of ABA, and hundreds of studies have been published demonstrating the efficacy of behavioral techniques for teaching children with autism (Horner, Carr, Strain, Todd, & Reed, 2002).

Moreover, in 1998, Jacobson, Mulick, and Green reported a study showing that intensive behavioral intervention is cost-effective in the long run, even though it is very expensive to implement short-term. Their research showed that if intensive behavioral intervention is provided during the formative years, fewer children require services after first grade through adulthood.

Parents as Leaders in the Effort to Solve the Autism Puzzle

Parents of children with autism ("autism parents") have been involved at all levels in the search for and support of appropriate interventions. They have founded non-profit groups such as Cure Autism Now (CAN), Autism Speaks, and Unlocking Autism. Parents of children with autism are also primary participants in the Defeat Autism Now (DAN) biomedical movement, and many are serving as researchers into the possible environmental triggers associated with autism. Parents are testifying at congressional hearings, appearing on national television shows, opening autism schools and clinics, and authoring books about autism.

My personal journey with autism began in the late 1990's when my first-born son, Lucas, started to show signs of the disorder at the age of 18 months and then received the official diagnosis one day before his third birthday in July of 1999. My life changed drastically from that point on. I have been transformed since that time from autism novice to autism expert. Within three months of the diagnosis, after reading the Maurice books and researching the disorder, I began to implement a Lovaas type ABA therapy program with my son. I then became Founding President of the Autism Society of Berks County, Pennsylvania. After attending hundreds of lectures on autism, I began to receive invitations to present my own experiences at local, state, and national conferences. Then, in 2003, I completed the requirements for certification in applied behavior analysis (BCBA). At the same time, I began working as the lead behavior analyst for the Pennsylvania Verbal Behavior Project and subsequently co-authored a paper reporting the results of a single-subject research study that I designed to teach my son tacts (Barbera & Kubina, 2005). In May 2007, I co-authored a book entitled *The Verbal Behavior Approach: How to teach children with autism and related disorders* (Barbera & Rasmussen, 2007), which is written from my perspective as both a parent and professional.

Parents as Board Certified Behavior Analysts (BCBA)

In addition to leading the autism grass roots effort, some parents have chosen to implement behavioral interventions with their children and to complete the requirements leading to the BCBA credential. The BCBA credential is awarded by a national organization known as the Behavior Analyst Certification Board (BACB). This organization was formed in 1998 for the purpose of insuring a minimal standard of expertise among professionals who offer behavior analytic services. The need for a formal certification process became evident in the mid to late 1990s when a demand for services began to be addressed by individuals who lacked the proper training. In this context, the BACB sought to protect consumers from unqualified professionals and to assist them in identifying those with the proper credentials (Shook & Neisworth, 2005).

Two levels of certification are offered by the BACB, including Board Certified Associate Behavior Analyst (BCABA) and Board Certified Behavior Analyst (BCBA). Both credentials require the applicant to have completed course work in ABA, to have completed clinical work under the supervision of a BCBA professional, and to pass a national certification exam. A detailed description of the academic and practical requirements associated with each credential has been published by Shook and colleagues (e.g., Shook, 2005; Shook & Neisworth, 2005; Shook, Johnston, & Mellichamp, 2004; Shook, Rosales, & Glenn, 2002; Warkomski, 2000).

The BCBA credential requires an applicant to have completed a master's degree, to have earned at least 15 credits of post-graduate courses in ABA, to have completed a practicum experience supervised by a BCBA professional, and to have passed the national BCBA exam. The required coursework is offered by over 72 Universities across the country, including several that offer on-line courses, thereby increasing the accessibility of this option to a wider range of consumers, including parents of children with autism (Shook & Neisworth, 2005).

Unfortunately, there is at present no way to determine the number of BCBA professionals who are also autism parents. A registry of BCBA professionals exists and is available on various websites (e.g., <http://bacb.com>). This registry makes it possible to identify BCBA professions in relation to geographical location, but it is not possible to search the registry for BCBA autism parents (Shook, 11-27-06, personal communication). I personally have contact information for only nine parent-BCBA professionals, including myself. However, it is reasonable to assume that there are others across the country, and this is an issue that should be explored further. A Yahoo Group was recently established as a forum for autism parents with BCBA credentials, and this may help to identify participants for future studies (autism_parent_BCBA@yahoo.com).

Another important issue in need of research is the unique perspective that autism parents with BCBA credentials may bring to the table as coordinators of behavioral intervention programs. Statements are often made suggesting that these parents provide a unique perspective. For example, one third of the consultants of the Pennsylvania Verbal Behavior (VB) Project are autism parents, and the VB project handbook states that, "parent-consultants bring a perspective to the Verbal Behavior Project that ensures a family-centered approach" (PA Verbal Behavior Project Family Handbook, 2006, p. 6). Similarly, in her review of *The Verbal Behavior Approach*, Weiss (2007) states, "The messages for parents in the final chapter are especially compelling. It is here that one can really see the benefit of (Barbera's) experience on both sides of the parent-professional partnership."

The contributions of autism parents with BCBA credentials can be considered on other levels as well. One has to do with the impact of expertise and competence that comes with specialized training.

For example, some researchers have suggested that children perform best when their families acquire skills and knowledge along with the confidence to apply that knowledge (Dunlap & Fox, 1999; Kuhn & Carter, 2006). Another level has to do with stress management. Studies show that stress is highest and most persistent in families where children are aggressive. However, parents with a professional background in ABA are likely to have a better understanding of how to prevent and treat problem behaviors so that aggression is reduced or avoided altogether. Finally, while most parents do not enter the field of ABA as professionals, those who do might be particularly adept at training novice parents. If that is the case, agencies who recruit ABA professionals may be particularly interested in recruiting autism parents as part of their staff.

In sum, there are a number of theories about the unique contributions of autism parents with BCBA credentials. However, these theories have not been supported empirically. If autism parents do make a unique and substantive contribution to the treatment process, then these contributions should be identified and integrated programmatically. Further research is needed to assess these issues.

Models for Studying the Development of Expertise

The process of developing expertise in autism and in ABA has not been studied in detail. Some studies outline professional and parent training on specific methods or general ABA procedures. However, research that explores the development of expertise in both autism and ABA has not been conducted. To do so, it would be helpful to have a model against which an individual's performance can be compared. Two such models are summarized below.

Novice to Expert Model

The Novice to Expert model was developed by Samuel Dreyfus (a mathematician) and Hubert Dreyfus (a philosopher) based on studies involving chess players and airplane pilots (Dreyfus & Dreyfus, 1980). According to its authors, students in any field pass through five levels of proficiency, including novice, advanced beginner, competent learner, proficient learner, and expert. At each level of the model, changes occur in three general aspects of skilled performance. First the learner moves from reliance on abstract principles to the use of concrete experiences. Secondly, the learner's perception changes as he or she begins to see things as a complete whole in which only certain parts are relevant. Third, the learner changes from being a detached observer to becoming an involved performer (Benner, 2001). While this is seen as the general sequence of progression, Dreyfus and Dreyfus (1986) note that not all learners become experts.

The Novice to Expert Model has been widely used to classify and study the acquisition of skills by learners in a variety of professions, including education and nursing (e.g., Brenner, 2001). However, despite its wide application, some researchers criticize the model and challenge the notion that skill acquisition occurs in a step-wise progression (Dall'Alba & Sandberg, 2006).

Dall'Alba and Sandberg's Model

Dall'Alba and Sandberg (2006) suggest that professional development involves both formal education and skill obtained "on the job." They propose a model with both horizontal and vertical dimensions. The horizontal dimension refers to skill progression that develops with practical experience

and the vertical dimension refers to the knowledge that develops with formal training. Key to the Dall'Alba and Sandberg model is that horizontal and vertical progressions do not occur in a step-wise fashion, thereby accounting for different patterns in the development of expertise. However, research into the use of this model is limited. For example, research is needed to understand what constitutes a particular professional skill and how this particular skill or expertise develops over time.

Studying the Development of Expertise in Autism and ABA

In some ways, the Dall'Alba and Sandberg (2006) Model may offer advantages over the Novice to Expert or other stage models for studying the development of expertise in ABA by autism parents. That is because autism parents are frequently forced to address the needs of their children for months and sometimes even years before they receive access to appropriate services or support. As such, these parents would gain "on-the-job experience" (progressing on the horizontal axis) before they began to acquire formal knowledge (progressing on the vertical axis). However, the appropriateness of using this or any model remains to be demonstrated, and the current study was designed to obtain preliminary information that could suggest which of the two models might be the best fit.

The Experience of Families Living with Autism

Most of the research on autism and families published to date has focused on three issues: diagnosis, services, and coping with stress (National Institute of Child Health and Human Development, 2001). The present study addressed a subset of these issues including (1) the general experiences of parenting a child with autism, (2) coping with stress, and (3) ABA service delivery. Current literature in these areas is summarized below.

Parenting a Child with Autism.

In recent years, a number of studies have begun to document the experiences of families caring for a child with autism. For example, Cashin (2004) conducted a phenomenology study involving nine such autism parents. These parents reported profound changes to self. Cashin summarized their reports by stating that "autism creeps into the selfhood of the parent not unlike a cloud of smog insinuating into a city on an otherwise cloudless day" (p. 166). Cashin identified several other themes in the data, indicating that parents experience less spontaneity, decreased social contact, fewer material things, and less time to pursue their own individual interests. However, positive experiences were also reported. For example, parents described rare moments when they truly connected with their child, and they noted tremendous personal growth in patience.

Hutton and Caron (2005) examined the impact of autism on 21 parents of children with autism. In this study, different parents reported experiencing many of the same feelings of frustration and stress. The parents also indicated feeling the constant need to plan ahead while having little personal time for relaxation or fun.

A qualitative investigation by King et al (2006) included 15 parents of children who had either autism or Down syndrome. Several themes were revealed by the data. Most parents stated that raising a child with a disability was a life-changing experience resulting in lost dreams, adaptation over time, and changes in world views. However, many also talked about positive contributions made by their children.

For example, they indicated that caring for their children had helped them (the parents) develop patience, acceptance, tolerance, perseverance, compassion and unconditional love.

Two recent dissertations used qualitative research methods to explore the experiences of autism parents. The first of these was conducted by Glass (2001), who is himself the father of a child with autism and founder of an autism center in Virginia. His dissertation describes a phenomenology study involving six sets of parents. Themes that emerged from the data included the importance of spousal support, the need to adjust expectations and live in the present, the necessity to “divide and conquer,” and the ability to find joy in the “little things.” In addition, parents reported feelings of avoidance, grief, anxiety about the future, social withdrawal, anger, embarrassment, sadness, intensity and ambiguity.

The second dissertation described a case study by Johnson (2006) which adapted and utilized Glass’ (2001) interview questions for studying the effects of autism on families and educators. Four themes that emerged from the data included the apparent lack of understanding by others in the social environment, the emotions associated with raising a child with autism, the importance of support systems, and the stress involved in working with the educational system. Johnson also found that the amount of stress experienced by parents and educators seemed to be related to the severity of behaviors produced by the child with autism.

Parent Stress and Coping

A number of quantitative studies have addressed parent coping and stress levels experienced by autism parents. Much of the literature suggests that mothers and fathers of children with autism report significantly more stress than do parents of children without disabilities or parents of children with other disabilities, including chronic illnesses (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Gray, 2002; Hastings & Beck, 2004).

In Gray’s (2002) longitudinal ethnography, more than half of the mothers reported persistent career problems, indicating that their child’s autism prevented them from working at all or restricted the number of hours they could be employed. On the positive side, parents reported an overall reduction of stress over time. For example, two-thirds of the parents indicated that their present situation was better than it had been a decade earlier. However, several exceptions to this finding involved the report of ongoing high stress levels among parents whose children were aggressive.

On the side of coping, Singh and colleagues (2006) suggested that stress levels can be reduced by teaching parents how to handle problem behaviors, including aggression. Hastings and Beck (2004) also noted that when interventions result in children’s language acquisition and in the reduction of problem behaviors, parents experience a greater sense of well-being and a reduction in reported stress levels.

The Impact of Behavioral Intervention

The belief that autism is curable leads many families to pursue treatments designed to cure the disorder (Levy and Hyman, 2003). Most educated parents with a newly diagnosed child will research the condition and learn that ABA has led to “recovery” for at least some children. This in turn will prompt them to implement an ABA program as soon as possible. But most parents have no idea when they make this decision how life-altering it will be.

Dillenburger, Keenan, Gallager, and McElhinney (2002) suggest that empowering parents is central to ABA treatment success. They note that parents can and should be trained to become their own

child's therapist. By learning both content and hands-on techniques, parents are often able to take back some control over their family life.

Coordinating in-home ABA programs involves hiring staff, managing data and assisting ABA professionals in making data-based programming decisions (Weiss & Delmolino, 2006). In-home and school-based ABA programs can also be financially crippling to families, sometimes costing more than \$40,000 per year (Glass, 2001). With such a large investment of time, energy, and money, it is not surprising that parents who choose to implement ABA home programs for their children are highly motivated to learn all they can about ABA.

Dunlap and Fox (1999) suggest that children with autism have a better prognosis if their families acquire skills and knowledge, especially if they can go on to use these skills to solve problems and create appropriate learning environments for their children. In addition to possessing skills to help their own child, successful families also must be familiar with professional services and be able to navigate systems to access services when needed. In a study of 170 autism mothers, Kuhn & Carter (2006) found that those with the most autism knowledge reported assuming very active roles in promoting their child's development.

Symon (2005) coordinated a week-long parent education program and reported that parents not only became proficient in the techniques but were able to go home and train others. Further, she stated that her study "placed parents in a role that is usually reserved for professionals, that of the expert trainer."

Summary

This review of the literature has illustrated the important role played by parents in defining the nature of autism, in searching for autism treatments, and in assuming leadership roles as autism experts and ABA professionals. It has also provided information about the experience of families living with autism, coping with stress, and participating in their children's behavioral intervention programs. Further, this review has provided information suggesting that autism parents who choose to pursue a career as ABA professionals may bring a unique perspective to the table. At the same time, no studies have been conducted to assess either the level of expertise demonstrated by autism parents with BCBA credentials or the unique perspectives which these individuals bring to the table in their role as professionals.

Purpose

The present research was designed to obtain pilot data to explore the perception of autism parents with regard to the following issues:

1. Why, how, and when do parents decide to pursue BCBA certification, and what is the experience of their journey from novice to expert?
2. What is the experience of parents working as BCBA professionals?
3. What type of training could best support parents with newly diagnosed children in becoming proficient in using ABA strategies?

Methods

Recruitment of Participants

As indicated above, there is no way at present to examine the registry of BCBA professionals for the purpose of locating those who are parents of children with autism (Shook, 11-27-06, personal communication). Therefore, participants can only be recruited by requesting volunteers from organizations that hire BCBA professionals. In this case, six of the author's BCBA co-workers were known to be mothers of children with autism. All six were sent an invitation via e-mail to participate in the study with the understanding that participation was voluntary. All six agreed to do so, and all six were assured that confidentiality would be maintained with respect to any specific identifying information.

Participants

Six mothers of children with autism participated in this study. Information about each participant was obtained through a questionnaire. Table 1 summarizes characteristics of the group. The mother's ages ranged from 39 to 50 years, and the length of time during which the BCBA credential ranged from 1 to 4 years. The ages of the participants' children (four boys and two girls) ranged from 8 to 17 years. Severity levels also varied. Two mothers reported that their children had mild autism as both of these children are functioning in regular education settings with little or no support. The other four children were reported to be functioning in the moderate or severe range of autism and currently spend the majority of their school days in self contained autism support classrooms. Participant number five reported that her daughter was diagnosed with mental retardation, deafness, visual impairment, and cerebral palsy in addition to autism.

Table 1. Characteristics of the participants and their children

| Participants' Characteristics | | | Characteristics of Participants' Children | | | |
|-------------------------------|---------------------------|--|---|-----|--------------------|--------------------|
| Ages | Length of BCBA Experience | | Ages | Sex | Official Diagnoses | Estimated Severity |
| 39 | 2 years | | 8 yrs | M | Autism | Moderate to severe |
| 39 | 3 years | | 10 yrs | M | Autism | Moderate |
| 41 | 4 years | | 11 yrs | M | PDD-NOS | Mild |
| 46 | 1 year | | 11 yrs | F | PDD-NOS | Mild |
| 43 | 2 years | | 15 yrs | F | Autism* | Moderate to severe |
| 50 | 2 years | | 17 yrs | M | Autism | Moderate to severe |

* This child had co-morbid diagnoses of mental retardation, deafness, visual impairment, and cerebral palsy.

Instrument

A questionnaire was used to obtain each participant's responses. The questionnaire began with the following statement.

Thank you for agreeing to participate in this study. Below are some topics that represent the focus of my study. Please reflect on your experience as the mother of a child with autism and as an ABA professional as you respond. You are welcome to respond as much as you like in response to each question.

1. Describe why, how, and when you decided to pursue BCBA certification, including your journey from novice to expert.
2. Describe your experiences working as a parent-BCBA.

3. What type of training do you think parents of children with autism need in order to become proficient in the use of ABA techniques?

Data Analysis

The data for this pilot study consisted of the narratives provided by the participants in response to the prompts stated above. Following the guidelines established in qualitative analysis (e.g., Wolcott, 1994), the data were reviewed a number of times, and a pattern analysis was conducted to identify content themes. These themes, with representative quotations, are provided in the data summary, below.

Results

Question # 1 – Describe why, how, and when you decided to pursue BCBA certification, including your journey from novice to expert

This question yielded the longest and most elaborate responses. The six participants came from different backgrounds and careers (education, psychology, medicine, and business) but all felt educated enough to research interventions for their child soon after diagnosis. Most found that they enjoyed providing ABA therapy to their own child. This led them to seek more and more information about ABA and eventually to pursue certification. Five of the six participants held a Master's degree or higher prior to their child's diagnosis. All six women took advantage of distance learning programs to complete the required ABA coursework. Here are some sample responses:

“Before having a child with autism, I earned a master's degree in psychology, and worked in a variety of human service jobs. By the time my child was diagnosed, I had plenty of academic background to guide my search and decisions about interventions. I was able to make decisions based on scientific research. That led me to pursue ABA as the best possible treatment for my child's autism.”

“As a regular education teacher for 10 years, it was a natural transition for me. When we first hired a private behavior analyst, I noticed I was more interested in the procedures than the other "autistic" mothers. While I did have to shift my paradigm of what I thought education was, it was exciting.”

Most participants reported the need to leave a job or entire career soon after their child was diagnosed. Some became BCBA's because of the lack of qualified personnel available to meet the needs of their own and other children. One mother reported that her need to learn more was essential to prevent her daughter from being institutionalized.

“I had initially learned of ABA through Catherine Maurice's book, *Let Me Hear Your Voice*. We live in a rural area and there wasn't anyone 'local' that knew anything about ABA. It was hard to find the time to research anything at all. This was in the early 90's when few regular people had computers and the Internet was still 'young'. We didn't get a computer until 1995 and that is when I started to get the information I needed.”

“Soon after my son's diagnosis, I left my part-time job when I realized that researching and implementing intervention therapies and planning for his educational needs would be a full-time job.”

“As I researched the many treatment options for young children with autism, I found that Applied Behavior Analysis (ABA) was the only scientific method of intervention that was proven to benefit children with autism.”

“I quickly learned that parents who didn't have the educational background to evaluate research and advocate for the best treatments got far less than the parents who had the education and drive to search out the best.”

“While running the ABA program for my son, I realized that I loved this work and these children! The detailed nature of coordinating the program and developing relevant educational drills was a perfect fit for my strong organizational skills.”

“When my child became school age, I decided it was time to go back to work, and thought to try working with kids with autism. I quickly got a job as a Behavior Specialist but since I had no formal training (other than workshops provided by my daughter's consultant) -- I thought I'd soon be discovered as a fake. Instead, I discovered that I knew more than most of the other professionals working with children in the agency. I was shocked to discover how ABA had been watered down and misused, so that an intervention which started out as science had, at times, become at best useless and at times harmful to the children.”

“Another factor was that our ABA consultant had moved away, and that now that my child was in regular elementary education, it was a much harder battle to fight to get the school to pay for ABA consultation. Gaining the skills myself seemed like a less stressful solution.”

“I really feel like pursuing my BCBA was a matter of survival. When I finally got a diagnosis at age 7 I found, to my utter surprise and dismay, that there were no educated professionals on whom I could depend. Certainly not the speech therapist, the school teachers and specialists, not the pediatrician, not the neurologist, and not the psychiatrist. I could not afford to hire a BCBA from out of state nor could I find home staff who could deal with both my child's language needs and her extreme aggression. I had to educate myself in order to survive, to keep from putting my daughter in an institution. She went to regular kindergarten which was a disaster. Then she was placed in a room in the basement by herself with three adults who could (and did) physically restrain her throughout the day. I lost my job when she was kicked out of the school's after-school program.”

Most participants noted that major advocacy was needed to secure services; that learning about ABA and verbal behavior (VB) involved a steep learning curve; and that time was wasted along the way.

“This treatment was not easily available -- it took some heated meetings with the educational professionals in order to get them to provide funding for an ABA consultant -- we were shown a letter from a parent stating that ABA had caused post-traumatic stress disorder in their child. However, we were lucky as other parents had fought this battle before us and won -- and we knew that.”

“The supervisor would attend our consultations and was openly antagonistic. So much time was wasted by this battle and I was so angry about it. Eventually, we transitioned to the school district and they were somewhat ‘easier’ to work with but had even less expertise.”

“In 1999, I heard about Verbal Behavior and Vince Carbone. After attending a conference in NC where he spoke with Dr. McGreevey, I began to try to change our DTT program into a VB program. My son’s teacher had attended the same conference so we worked together to try to make the changes and implement the program but it was difficult. We had the ABLLS but since my son was non-vocal, we weren’t sure how to score parts of it, etc. Again, a lot of valuable time wasted.”

Most women stated that their learning continues and that they and/or others do not consider themselves experts.

“The road to "expert" is still on-going. My knowledge has grown exponentially through my experience working (as a BCBA) as well as mentoring from more experienced colleagues and attending training sessions and reading journal articles and books.”

“I currently struggle with the desire and need to spend more time in research and study and the demands of my own child which continue to be great. I am sure my "growth" has been both slowed (because of the time limitations) and expanded (because of personal experiences) because I am a parent of an autistic child.”

Question # 2- Describe your experiences working as a parent-BCBA professional

Responses to the second question yielded mixed results. The participants generally reported feeling positive about their work as a BCBA and most stated that being a parent of a child with autism helped give them perspective on both “sides” and helped them develop “trust” with other parents.

“In short, I find it an amazing experience. I feel like I have the best of both worlds. I can totally relate to the professionals in the field, while having the benefit of also being able to relate to and understand parents. It is a definite plus, as I have found that parents will quickly let down their walls and "trust" me a lot easier than they would someone who is not a parent. “

“The most interesting aspect of working as a BCBA and being the parent of an autistic child is being able to relate to all sides of the experience. I find myself very protective of parent interests especially within the school setting.”

“I try to provide some insight into what the home situation might be. I like to think that I am helping not only the learners with autism but also serving as someone that makes the professionals think about what may really be happening and that many of the parents are simply overwhelmed and don’t know what to do about their situation. Maybe this will make communication between the home and school more effective or at least less like two different sides who can’t agree with each other. Maybe less time will be wasted on the petty stuff. “

“Seeing a variety of schools and how they handle kids with autism, has really given me a lot of perspective on my own daughter's situation. I know that her school could be better -- or way worse. I have a better understanding of the school system.”

“I am able to draw on my own experiences of not only what worked for me and what didn't but also the toll of intervention on the family. I have been able to provide services for many families for free in order to get them started and so they can see the value of the intervention for their child and their child can get started with language.”

“There is also the benefit that everything I learn from working with others and from training I can apply directly to the benefit of my own child.”

A few parents reported conflict and guilt related to fulfilling both roles.

“Many things about the job are frustrating, and make it tougher to be the parent my own child needs -- the random hours and driving all around make me tired and frazzled. I feel like I am constantly juggling schedules, and there is never enough time.”

“There are so many crossovers and double points of connection -- many times, my own daughter is in activities or therapy with my clients. This hasn't really been a problem though, but it is a constant in my life. I even got a release of information which allows me to talk to my older daughter, who is a Karate instructor for one of my clients.”

“Being perceived as a "mom" is more of a detriment in schools. When I am working with parents (in homes), the parents respond very positively to my specific understanding of their situations, they love that I am a mom too and really understand what they are going through. Having this parent perspective can lead to lack of trust in a school situation, where I can be seen as not being on the school's side.”

“Unfortunately, I've come across some ABA professionals who promote the idea that an ABA consultant without a graduate degree in a related field (either Master's in ABA and/or Masters in Clinical Psychology) is not qualified to be a behavior consultant. At least one professional referred to me as a “business person” and, as such, not qualified. While these unfounded statements are annoying, I know that my unique set of skills and experiences have proven me to be a competent behavior consultant.”

“There is quite a bit of guilt when I find myself spending more time and energy with the autistic children of other parents (I have to make a living) than with my own child. Because then I think about the reason I got into the field in the first place. If I did some other line of work there would be a clean distinction between the two - work to make a living and work with my child. Now I am doing the work my child needs from me - but I am doing it more often with other children - and I am still having to depend to a large degree on others for my own child's education. There is just not enough of me to go around.”

Question # 3- What type of training do you think parents of children with autism need in order to become proficient in the use of ABA techniques?

BCBA mom participants varied in their responses regarding training of novice parents when answering question number about the type of training they think parents of children with autism need in order to become proficient in ABA techniques.

“This is a very tough question to answer because the amount of training needed depends on a parent's current foundation of knowledge. I have met with parents who were trained as

teachers, lawyers, doctors who can master and apply principles with very little training and then there are parents who have a great deal of difficulty grasping even the simplest principle of ABA.”

“At the minimum, a training series on the basics of ABA and VB (broken down into short trainings for easy understanding and "digestion") and more importantly TONS of guided practice.”

“I think the system of some current trainers of having a system of trainings that require pre-requisite trainings or skills and that build on each other is excellent especially when they also provide hands-on trainings along with the informational trainings.”

“Self-training programs that included video would be great but there would always be a need for guided practice to correct errors since in some instances small errors by an instructor can lead to major problems for a child.”

“I think videos examples and practicing with someone is great. I think parents should be trained to recognize mistakes people make or some of the “when this happens” kind of things. Maybe have some hands on “mistake identification”.

In addition to recommending ABA/VB overview training, participants also recommended that novice parents be training specifically on reinforcement principles, manding, prompt fading, task analysis, the functions of behavior, and behavior reduction strategies.

“I think parents need the basics in reinforcement. Most people don’t realize what behaviors to reinforce but worse yet, they don’t know how NOT to reinforce problem behavior. It would be very beneficial if parents knew how to determine the function of problem behavior and then how to teach a replacement for it. “

Overall, the training that most participants recommended was hands-on training with a qualified and experienced BCBA professional.

“Workshops can be useful, for the few people who are able to take information in as they are watching and remember enough to actually do it -- but this is rare. Hands-on workshops are more useful, but it is hard to have hands on workshops in many of the needed skills.”

“Finding a highly-competent person who is doing what you want to be doing and then working side-by-side with this person is key!”

“There just need to be more skilled practitioners to get out there in the schools and homes -- there are so few, and so few that are accessible to families with average or low incomes.”

Discussion and Conclusion

Ironically, 40 years after Bruno Bettelheim’s (1967) claim that autism is caused by detached, unloving, “refrigerator mothers”, mothers of children with autism have actually surfaced as some of the most effective advocates and educators of children with this disability. Many mothers are leaders and experts in the field of autism. They have helped to redefine the nature of autism as well as the nature of the treatment. The current study is only the first in this important line of inquiry.

This qualitative pilot study revealed several positive themes including: a natural progression from a variety of backgrounds; a passion for the work of behavior analysts; a love of learning new concepts to help their own and other children; advocating for all children to experience best practices in treatment; being able to gain the trust of other parents easily; and serving as a bridge between parents and professionals. Several of the six participants reported some negative experiences when dealing with professionals and also experienced some guilt, conflict, and time constraints in attempting to serve both parent and professional roles. When giving views on training, most of the participants stated that the best way to train novice parents was to provide them with guided practice from skilled professionals.

Limitations

The results of this study are limited in three ways. First, the majority of the participants were recruited and hired by me as co-workers in the same agency. Since I am a trusted colleague to these women, there is no doubt that my views may have influenced their attitudes. Secondly, there are only six participants in this study and five of them live in Pennsylvania, thus limiting the generalizability of the findings. Third, all six women organize their work in applied behavior analysis around Skinner's (1957) analysis of verbal behavior, although most have had previous experience with more traditional approaches to behavioral programming. Finally, there is no way to know whether the views of the participants in this study are representative of the views of the larger population of parent BCBA professionals.

Future research

The results of this study suggest the need for further research in relation to three primary questions: (1) Do autism parents who pursue a career in ABA differ from autism parents who do not? (2) Do autism parents with BCBA differ from BCBA professionals who have typical children or children with other disabilities? and (3) What is the most effective way to support the needs of parents with newly diagnosed children in learning behavioral skills to support their children?

In relation to the first question, it would be interesting to explore whether parent-BCBA professionals exhibit similar feelings of stress as parents who use ABA but are not ABA professionals or those who do not include ABA in their children's treatment programs. Theoretically, autism parents with BCBA could be expected to have lower levels of stress since they have the background and knowledge to treat problem behaviors and to teach their children useful skills. However, since these women live and breathe autism seven days a week both personally and professionally, this may produce more or different stress levels. Also in relation to the first question, future studies could compare the experience of parents who have become leaders in the field (e.g., authors, researchers, founders of autism-specific organizations, etc.) with the experiences of parents who have maintained a lower profile. Data generated in response to all of these issues could yield information that might assist in the development of programs to improve parent training and a reduction of stress for all parents.

Responses to the second question would address the need for information about BCBA professionals in general, as this field is in its infancy. It would be particularly important to determine whether there are elements of expertise associated with ABA more generally that differ from elements of expertise specific to supporting children and families living with autism. This type of information could help to clarify what constitutes a behavioral autism expert, how this expertise develops, and whether expertise in ABA alone is sufficient or ideal as a background for supporting children and families living with autism.

Finally, much more research is needed to find the most effective and efficient methods for training parents of newly diagnosed children with autism, since parents are pivotal to their child's success. The bottom line of all this research is to improve the lives of children and families living with autism. Helping parents to learn behavioral techniques for teaching positive skills (such as language) and for reducing problem behaviors (such as aggression) is likely to have the most direct positive influence on the quality of life for families living with autism.

References

- Barbera, M.L. & Kubina, R.M. (2005). Using transfer procedures to teach tacts to a child with autism. *The Analysis of Verbal Behavior, 21*, 155-161.
- Barbera, M.L. & Rasmussen, T. (2007). *The Verbal Behavior Approach: How to teach children with autism and related disorders*. London: Jessica Kingsley Publishers.
- Benner, P. (2001). *From novice to expert*. Upper Saddle River, N.J.: Prentice Hall Health.
- Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of self*. New York: Free Press.
- Carmichael, M. (06, November 27). A terrible mystery. *Newsweek, 52-53*.
- Cashin, A. (2004). Painting the vortex: the existential structure of the experience of parenting a child with autism. *International Forum of Psychoanalysis, 13*, 164-174.
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis*. Upper Saddle River, N.J.: Prentice-Hall, Inc.
- Dall'Alba, G., & Sandberg, J. (2006). Unveiling professional development: A critical review of stage models. *Review of Educational Research, 73*(3), 383-412.
- Dillenburger, K., Keenan, M., Gallager, S., & McElhinney, M. (2002). Autism: Intervention and parent empowerment. *Child Care in Practice, 8*, 216-219.
- Dreyfus, H. L., & Dreyfus, S. E. (1986). *Mind over machine: the power of human institution and expertise in the era of the computer*. New York: Free Press.
- Dreyfus, S.E., & Dreyfus, S.E. (1980) A Five-Stage Model of the Mental Activities involved in Directed Skill Acquisition. Operations Research Center Report
- Dunlap, G., & Fox, L. (1999). Supporting families with young children with autism. *Infants and Young Children, 12*(2), 48-54.
- Glass, P. (2001). Autism and the family: A qualitative perspective. *Dissertation Abstracts International, 65* (09), 3287A.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215-222.

- Hastings, R. P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry*, 45(8), 1338-1349.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.
- Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W., & Reed, H. K. (2002). Problem behavior interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disabilities*, 32(5), 423-446.
- Howard, J., Sparkman, C., Cohen, H., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26, 359-383.
- Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, 20(3), 180-189.
- Jacobson, J.W., Mulick, J.A., & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. *Behavioral Interventions*, 13, 201-226.
- Johnson, K.M. (2006). The effects of autism on families and educators: A case study. *Dissertations Abstracts International*, UMI 3205719.
- Kantrowitz, B., & Scelfo, J. (06, November 27). What happens when they grow up? *Newsweek*, 47-53.
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child Care, Health, and Development*, 32(3), 353-369.
- Kuhn, J. C. & Carter, A.S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76 (4), 564-575.
- Levy, S., & Hyman, S. (2003). Use of complimentary and alternative treatments for children with autistic spectrum disorders is increasing. *Pediatric Annals*, 32(10), 685-691.
- Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. New York: Knopf.
- Maurice, C., Green, G. & Luce, S.C. (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: Pro-Ed.
- McEachin, J. J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, 97, 359-372.

- National Institute of Child Health and Human Development. (2001). *Autism facts* (NIH Publication No. 01-4962 ed.) Rockville, MD: National Institutes of Health: Author.
- New York State Department of Health, Early Intervention Program (1999). *Clinical practice guideline: Report of the recommendations: Autism/PDD, assessment and intervention for young children*. Albany, NY: author.
- Pennsylvania Verbal Behavior Project: Family Handbook. Retrieved September 25, 2006 from: <http://www.pattan.net/files/Autism/VerbalBeh0106.pdf>.
- Perry, R, Cohen, I., & DeCarlo, R (1995). Case study: Deterioration, autism, and recovery in two siblings. *Journal of American Academy Child Adolescent Psychiatry, 34*(2).
- Rimland, B. (1964). *Infantile autism*. London: Meredith Publishing.
- Shook, G. L. (2005). An examination of the integrity and future of Behavior Analyst Certification Board credentials. *Behavior Modification, 29*, 562-574.
- Shook, G. L., Johnston, J. M., & Mellichamp, F. (2004). Determining essential content for applied behavior analyst practitioners. *The Behavior Analyst, 27*, 67-94.
- Shook, G. L., & Neisworth, J. T. (2005). Ensuring appropriate qualifications for Applied Behavior Analyst Professionals: the behavior analyst certification board. *Exceptionality, 13*(1), 3-10.
- Shook, G. L., Rosales, S. A., & Glenn, S. (2002). Certification and training of behavior analyst professionals. *Behavior Modification, 26*, 27-48.
- Singh, N. N., Lancioni, G. E., Winston, A.S., Fisher, B. C., Wahler, R. G., McAleavey, K., et al. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders, 14*(3), 169-177.
- Skinner, B.F. (1957). *Verbal Behavior*. Englewood Cliffs, N.J.: Prentice Hall.
- Symon, J. (2005). Expanding interventions for children with autism. *Journal of Positive Behavior Interventions, 7*(3), 159-173.
- United States Surgeon General. (2000). *Report of the Surgeon General*. Retrieved December 1, 2006, from <http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism>.
- Warkomski, F. (2000). Applied behavior analysis credential program in Pennsylvania and beyond. *Behavior Analyst Today, 1*(1), 18-20.
- Weiss, M. J. (2007). A Review of Mary Lynch Barbera & Tracy Rasmussen's The Verbal Behavior Approach: How to teach children with autism and related disorders. *Journal of Early and Intensive Behavior Intervention, 4* (2), 526-531.
- Weiss, M. J., & Delmolino, L. (2006). The relationship between early learning rates and treatment outcome for children with autism receiving intensive home-based Applied Behavior Analysis. *The Behavior Analyst Today, 7*(1), 96-116.

Wilson, A. (06, June 20). Special challenges: Parents of autistic children measure progress in small steps. *Reading Eagle*, p. B1.

Wolcott, H.F. (1994) *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage

Author Contact Information

Mary Lynch Barbera, RN, MSN, BCBA
P.O. Box 170
Robesonia, PA 19551
484-336-3239
MLBarbera@aol.com

**ADVERTISING IN THE
JOURNAL OF SPEECH - LANGUAGE PATHOLOGY AND
APPLIED BEHAVIOR ANALYSIS**

The prices for advertising in one issue are as follows:

1/4 Page: \$50.00 1/2 Page: \$100.00 Full Page: \$200.00

If you wish to run the same ad in multiple issues for the year, you are eligible for the following discount:

1/4 Pg.: \$40 - per issue

1/2 Pg.: \$75 - per issue

Full Page: \$150.00 - per issue

An additional one-time layout/composition fee of \$25.00 is applicable

For more information, or to place an ad, contact Halina Dziewolska by phone at

(215) 462-6737 or e-mail at: halinadz@hotmail.com