

AUTISM AND THE FAMILY: A QUALITATIVE PERSPECTIVE

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Dissertation submitted to the Faculty of the Virginia Polytechnic Institute and State University in partial fulfillment of the requirements for the degree of

Doctor of Philosophy
in
Human Development

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September 20, 2001

Falls Church, Virginia

Keywords: Autism, Family

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(ABSTRACT)

The focus of this dissertation was to gain a better understanding of autism, and its effects on family life. Studies have been done on the behavioral and cognitive effects of autism on the affected child, and how those effects manifest themselves into family life. No studies were found, however, that give a rich, qualitative account of what it is like to live with autism using first hand accounts as data, and what and how families are learning in the process.

Using a phenomenological framework, this study was comprised of interview and observational data collected at the homes of six families with an autistic child. Selection criteria required that participants be parents living with the clinically diagnosed autistic child and, willing to participate in a study that would allow the researcher home visits. The data were analyzed using qualitative software (NVivo) and themes began to emerge. The themes were used to answer the question: What is the experience of living with an autistic child, and what does that experience mean?

Knowledge was added to the current literature on autism in the areas of spousal support, expectation adjustment, finding joy in the “little things,” avoidance, grieving, anxiety about the future, support systems, social withdrawal, divide and conquer, anger, embarrassment, sadness, intensity, living in the present, and ambiguity.

Many themes generated by this study becomed future research. Included in this grouping: (a) The placement of anger generated by the implications of living with an autistic child. (b) The lack of sibling interaction and its affects on the families. (c) The stability of the family prior to the diagnosis concerning the adaptive or maladaptive response to the diagnosis. (d) The role of spousal support in the autistic family.

Knowledge generated by this study can be used in a variety of educational ways: (a) the education of the family with an autistic child, (b) the education of professional caregivers that treat the child, but have a poor understanding of what family life may be like and, (c) law makers, insurance companies, the general public, and our schools could be made more aware of autism and family life, again allowing some degree of empathy to understand the hardships these families endure.

ACKNOWLEDGMENTS

After twenty years out of a classroom I hesitantly made the decision to return to enhance my recent career change. Little did I know it would change life in a profound way. I was caught up in the every day rush of life not allowing time to focus and reflect on the things that were most important to me. My family and work were becoming a routine. My classes changed all of that, and made me look at life from different perspectives. My first classes were with Marcie Boucouvalas, my journey began, and I thank you. I also wish to thank Marcie for being my chair, giving me direction on the topic, and all of the countless hours she must have spent reading, and re-reading my dissertation enabling me, with her advice, to produce the finished product.

I spent four semesters in research classes with Marilyn Lichtman. Without those classes, and her guidance this project would not have been possible. I thank her for the time, and guidance she has given me. Marilyn has gone the extra mile, I'm grateful. Classes with Linda Morris provided a framework from which to gather and process knowledge. I thank her for her classroom abilities and also her reading and input. I also thank Judy Pearson for her reading and input. Judy taught a course in family communication, which provided me with tools for my project, but also provoked exploration into other areas of family systems. Mitch Taubman, a clinical psychologist, has always provided valuable insight at the Autism Learning Center, and encouraged me to pursue this topic. I thank him for that, reading, and his input.

My family has been supportive and patient throughout my learning experience. My wife, Leslie, encouraged me from the beginning, and during classes spent many a night home alone with the kids. I thank them, and look forward to spending more time with them. I also wish to thank my fellow doctoral traveler, Jon Boyle, who offered encouragement, insight, and friendship.

My twelve participants deserve a great deal of thanks. They welcomed me into their homes, and shared very personal information about their lives with their autistic child. I feel extremely honored that their trust and friendship was given to me.

This dissertation would not be possible without the people listed above. From the first classroom experience to the final stroke of the keypad all have been an influence. A heartfelt thanks to all.

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Chapter I: Introduction

Intent of Chapter I

The purpose of this chapter is to discuss the background and need for the study, as well as its significance and aim. As a foundation, the chapter will also provide historical and clinical knowledge concerning the causes, behavioral issues, and treatment of autism. This background information is essential as a backdrop. A better understanding of the phenomenon of autism and its effects on family life is the ultimate intent of the study via a qualitative examination of the experience.

Background of the Problem: Understanding Autism

The problematic foundation of autism in the family centers on autism and its biological and behavioral manifestations. Childhood is a demanding and challenging period for all parents, and when a child has a problem, the demands and challenges are magnified. When the problem is autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope. This study is about autism as experienced by the families of children with autism. The study will probe into these parents' extraordinarily difficult odyssey of learning and transformation. As one prominent researcher in the field put it, " I think sometimes ... the parents hurt more than the kids" (Lovaas, 1991, p.3). This section provides an overview of autism and is key to placing autism in the context of the family throughout the dissertation.

Leo Kanner, a former child psychologist at Johns Hopkins University, first introduced autism to medical literature in 1943. According to Coleman (1989, p.3), Kanner chose the word “autistic” because the children had in common an “extreme aloneness from the beginning of life and an anxious, obsessive desire for the preservation of sameness.” The author notes that in the previous decade, theories of mental illness were developed that blamed the illness on the parents who raised the child. Because there were no physical abnormalities, it was surmised that the disorder must be caused by faulty nurturing on the part of the parents (Sanua, 1986), especially the mother, hence the term “refrigerator mother.” Fortunately, autism is now understood as a neurological syndrome and autistic symptoms are recognized as the final pathway with which the brain expresses a great variety of lesions and malfunctions of the infant central nervous system (Coleman, 1989).

Causes of Autism

Little is known about what causes autism, but some theories exist. Autism research reports suggest that autism is the result of a dysregulated immune system in children that is triggered by a virus or genetic disposition. Or autism may be caused by intrauterine, prenatal, or neonatal stress or trauma (Waldron, 2000). Dr. Andrew Wakefield, of the Royal Free Hospital in London, published a study of 12 autistic children who also had persistent gastrointestinal problems. Wakefield reported that the weakened measles virus used in the MMR vaccine had infected the children’s intestines, disrupting the normal processes by which nutrients are absorbed by the blood and brain, and harmful substances are

denied entry (Cowley, 2000). Studies in 1995 proposed autism as a genetic disorder, based on evidence gathered in a British twin study (Bailey, LeCouteur, Gottesman, Bolton, Simonoff, Yuzda, and Rutter, 1995). The possibility of a link between environmental toxins and autism has also been suggested (Toxic waste site: link to autism?, 1990). Bauman and Kemper (1985), through the use of magnetic resonance imaging, found significant underdevelopment of the cerebellum in nonretarded autistic individuals. The explanation of autism will only be complete when the necessary causal links have been traced between gene, brain, mind, and behavior.

Behavioral and Cognitive Effects on Individuals With Autism

Whatever the causes may be, the effects of autism on the cognitive and behavioral processes of children are devastating. Autism is a severe disruption of the normal developmental processes that occur in the first two years of life. Autism leads to impaired language, cognitive, social, and adaptive functioning causing the children to fall farther and farther behind peers, as they grow older. Autistic individuals seem not to understand simple verbal communications, are confused by sensory input, and withdraw in varying degrees from people and the world around them. They become preoccupied with seemingly meaningless activities, objects, and repetitive behaviors (Brook, 1992). Their problems seem to be related to perception. Autistic individuals seem lost in their own inner world. Uta Frith (1993) has theorized that one major cognitive deficit may account for all of the problem behaviors and isolation. Her evidence suggests that individuals with autism do not have “the ability to think about thought, or to imagine

another individual's state of mind" (p. 112). Because of insufficient development of a theory of mind, people with autism lack the ability to engage in imaginative ideas, to interpret feelings, and to understand intentions beyond the literal content of speech. Another example of perceptual abnormalities is evident from brain imaging studies. The autistic brain processes facial images in the inferior temporal gyrus, a region typically used by the normal brain to process inanimate objects (Cowley, 2000). Research by Perner, and Leekham (1989) at the University of Sussex reports that autistic individuals have difficulties in the appreciation of facial, bodily, and vocal expressions of feeling states. Autistic people have also been found not to use gestures that express mental states such as embarrassment, but to use gestures such as beckoning that aim at manipulating behavior.

Coleman (1989), reports that evolving manifestations of autism may begin as early as the first hour of birth. Symptoms such as the failure of infants to mold in the mother's arms, and sensitivity of the tactile system causing the child to scream or stiffen when held. Their gaze is described as empty and inwardly focused. Most symptoms manifest themselves or become detectable between 17 and 36 months of age (Vostanis, 1994). The author reports the reasons for the delay in diagnosing autism at an early age may be related to the nature and development of the condition, to lack of specialized training, to absence of services, or to the absence of appropriate standardized assessment procedures.

The most important thing to realize is that autistic behaviors do not happen in a vacuum. They happen in a family system and therefore, they affect family life. For example, if a child with autism does not sleep through most of the

night the parents will be affected. We have all heard the stories of parents of normal newborns, who, during the first few weeks or months, do not sleep through the night. Imagine having a child with autism, who, for the first twelve or more years of life not only does not sleep during much of the night, but also spends that time yelling, singing, repeating conversations, roaming around the house, and/or trying to leave the house.

The hardest thing to appreciate, if you are not the parent of an autistic child, is the relentless nature of the symptoms of autism. Many behaviors occur repetitively for long periods of time. To give a specific example: in a recent study, a boy with autism said, "Can I talk?" 618 times during one 3-hour period of observation (Coggins & Frederickson, 1988).

Other common behavioral characteristics of autism vary widely from child to child, but some are prevalent in most autistic children. Obsessive behaviors such as not stepping on cracks in the sidewalk, retracing exact steps to locations that are familiar, and repetitive flapping of the arms and hands are present. Other characteristics of autism include poor or non-existent toilet skills, refusing food, aimless wandering with no fear of getting lost, climbing on dangerous and inappropriate objects such as kitchen counters, roofs, railings, and little or no communication. Echolalia, the repeating of sounds and words, is quite common. Autistic individuals repeat words, sentences, and sometimes-whole songs and movies. They may excel on the computer, yet cannot ask for a glass of milk, and in some cases cannot chew food. There is no comprehension of hygiene, or respect for others or their property. Bizarre body movements and

stiffening of the body are often present. Biting, pinching, and hitting, themselves and others, is usually accompanied by tantrums.

Treatment of Autism

Cognitive skills are present in autism but seem to function at a low level. Generalization and association are usually learned by repetition. Some skills are mastered through long periods of trial and error. Some professionals feel that, because individuals with autism fail so often, they tend toward a state of learned helplessness, which may further depress their motivation to learn. The challenge for educators, therapists, and parents is to avoid or minimize opportunities for failure, while finding meaningful reinforcers for success. This is a huge challenge. Early initiation of programs which employ a one adult-to-one child ratio, and which contain a high degree of structure and continuity have shown an elevated degree of effectiveness. Several programmers of early intervention for children with autism, including children as young as 18-40 months, have reported satisfactory outcomes (McEachin, Smith, Lovaas, 1993). A program proclaiming one of the highest success rates is headed by Dr. Ivar Lovaas at the University of California in Los Angeles. This program uses intensive behavior modification beginning early in life. In one study, 47% of high functioning children with autism treated in their program (40 hours per week) achieved normal functioning in two realms, the intellectual and the educational (Lovaas, 1987). Initially, Lovaas's program was touted as a cure, but later in a letter to his colleagues, Lovaas refuted the word cure, which he said would imply a removal of the presumably organic basis for autistic behavior (Lovaas, 1991).

Although the work by Lovaas is most commonly cited, there is evidence that other early intervention programs result in substantial benefit. Harris and Handleman (1994) present information on ten different preschool education programs for children with autism.

Serotonin reuptake inhibitors (SRI) are now being used as medications to stabilize mood-altering serotonin in the brain. Autistic individuals have below normal levels of serotonin in the brain, and the use of these medications has been shown to reduce inappropriate behaviors (Waldron, 2000). Other drugs, such as Thorazine and Haldol, may also reduce some undesirable behaviors, such as temper tantrums and aggression, but may also produce undesirable effects, such as seizures, facial grimacing, or tongue protrusions.

Alarming Statistics

Autism is now a national emergency. In the past ten years there has been a 273% increase in the number of children with autism who enter the developmental services systems of our schools (Yazbak, 1999). The incidence of autism has risen. Numbers of incidences vary from 15 to 40 per 10,000 births, and is now the third most common developmental disorder affecting children (CD Publications, 1999). Congresswoman Morella, MD, stated, "Autism is more prevalent than Down syndrome, childhood cancer, and cystic fibrosis; yet autism receives less than 5% of the funding of these other disorders combined. As a nation, we must provide more treatment and earlier intervention so that our children can reach their maximum potential in life (Dean, 1999, p.1)."

There has been much speculation about the increase of autism. Some speculate that the increase is due to diagnostic clarity and increased familiarity (Stokstad, 2001). However, the fact remains autism is a prevalent developmental problem.

Clarification of the Issue: Lost, Confused, and Uneducated

An autistic child in the family creates a situation that requires understanding and support from extended family, friends, the community, and professional caregivers. Unfortunately, most families with an autistic child know little about autism as a disease, or its implications involving the above mentioned systems. Educational sources are minimal, and most research involving autism, as shown in the literature review, is quantitative and mostly unreadable by the general public. Furthermore, the research, again per the literature review, concentrates on specific stressors, behaviors, or psychological implications of autism, and the effects on the parents. I am not suggesting the importance of these studies be minimized; they have been key in forming the understanding of autism, as we now know it; however, a more complete picture of autism involving systems that play a role in adaptation for the family is required. This can only be provided by a qualitative study, which will allow for the study of the first hand experience of living with an autistic child.

The experience, the reality of an autistic family's world, should be understood on three levels. First, autism should be understood by the newly diagnosed, or inexperienced autistic child's family now embarking on an atypical life-long journey. These parents are generally left in shock and disbelief, not

knowing what course of action to take to help their autistic child and their families, including the siblings of the autistic child, survive this devastating disease. They must learn to cope with stressful situations and accept a lifelong transformational learning process to continually adapt to changing circumstances.

Second, the experience should be understood by extended family, friends, and the community. If all could understand the experience of the autistic family, they could empathize, not sympathize; be supportive, not avoidant; be accepting, not rejective. Professional and paraprofessionals who work with families of individuals with autism must ensure that they are not inadvertently adding to the burdens of parents who are already stressed to the maximum. Professionals and paraprofessionals may include pediatricians, neurologists, psychologists, special education teachers, teacher's aides, behavioral therapists, speech therapists, dentists, and lawyers. In addition, policy makers and government officials at the local, state, and national levels, who have the power to help or hurt these parents by voting on research and policies affecting people with autism, must also understand the experience.

Third, is the link between the family and extended family, friends, community, and professionals. Support and resources provided by the above mentioned enable family adaptation to the crisis and enable a family to develop in a positive manner. After a long and exhaustive search of the literature, a theory or model could not be found specific to autism and family systems theory, or more specifically to family stress theory. How do autistic families fit into the

framework of family stress theory? What is the family's perception of their situation? Chronic illness, and of course, normal development is well documented. Autism, however, is different. Autistic individuals live a normal lifespan and need care literally from birth to death. Unlike mental retardation, their potential is not known, they may excel in one particular skill and may be severely lacking in all others causing parents to have high expectations. One hour the child may be alert, the next seemingly unaware of anything. The ups and downs of autism create great anxiety for the family, both short and long-term. There is also a lifelong grieving process that has no closure. Understanding the adaptational processes of a family with an autistic child will provide a framework for dissemination, by professionals, of valuable information on resources, coping mechanisms, and buffers a family may use to adjust and adapt to life with an autistic child.

Until the experience of the autistic family is understood, these families will continue to falter. They will continue to be needlessly persecuted and ignored by the community, by insurance companies, and governmental agencies. They will continue to receive inadequate and inappropriate diagnosis and treatment from professional caregivers. Relationships will continue to fail, and more families will dissolve. We must attempt to eliminate ignorance of the experience. History has shown if we do not understand and appreciate a culture, or a race of people, we generally dislike, and ignore them, excluding them from our lives. The same can be said of autistic people, people with AIDS, with Alzheimer's, and so on. Clearly, the problem of understanding and acceptance

must be overcome. “We recognize that their quality of life will be highly dependent on how society regards them, and to what degree it accepts them” (Trepagnier, 1999, p.40).

Purpose of the Study

The purpose of this study is to better understand, and document the effects of autism on families with an autistic child, and the coping mechanisms learned, and used, to counteract the effects so that we may gain a deeper understanding of what it is like to live with an autistic child, thus enabling education that is necessary for parents and the community as a whole. Understanding stressors, implications of the stressors, resources needed, and coping mechanisms employed by families with an autistic child enables us to provide valuable educational sources to families on the reality of autism in the family and ways to overcome this dismal diagnosis. Understanding by their extended families, friends, the community, and professional caregivers will allow empathy to the devastation wrought by autism. We must first understand the problem before we can learn what coping mechanisms and resources will enable a positive adjustment and adaptation for the family, and what roles extended family, friends, and community could assume to promote a permanent, and enjoyable family life for the family with an autistic child.

Research Questions

The purpose of the following research questions is to generate knowledge, which then might have implications for the education of adults on autism. The use of the word adults is inclusive to the population as a whole, not just

pertaining to professionals or parents. According to statistics, autism is an epidemic and needs to be understood by all. As I look back to my high school years (1969-1973) I remember the stigma attached to the students of the “slow classes” and their families by the community. Why were they hidden away and forgotten? Why were they and still are considered a burden by the school system and the community? Education is the key to awareness, and if education is the solution, we will need to answer the following questions:

1. What is the experience of living with an autistic child, and what does that experience mean?
2. What are the coping strategies families learn and use in response to stressful situations?
3. What are the family’s appraisals of the situation (the meaning the family attaches to the total situation)?
4. What resources (i.e. support from friends, community, and professionals) do families affected by autism utilize?
5. What are the internal enabling factors that sustain positive family adjustment?

Impact of the Study

The importance of this study is deeply influenced by my experiences of living with an autistic child. My son, Ryan, now six years old was diagnosed as autistic on his second birthday. My wife and I were devastated, and frightened; the world as we knew it was gone. We had heard of autism, but this sort of thing surely could not be happening to us. We were offered little advice and given a

grim prognosis on future life with an autistic child. Information was scarce; there were no specialists for autism. Family and friends could offer little comfort. How could they? Their understanding of the problem was even more minimal than ours. Somehow, with our two other children and Ryan, we had to adjust and live life happily as a family. Our best defense against helplessness and depression was action. After months of intensive research, September of 1997 saw the opening of the Autism Learning Center, a non-profit provider of behavioral therapy, which is clinically designed for autistic children. We now provide services for twenty-four children and their families, and work with the public school systems where the children attend school.

We still struggle on a daily basis. The implications of the stresses of living with an autistic child seem to mushroom on a daily basis. Grief and anxiety about the future loom heavily, but my wife and I are determined and on most days we look at our situation as a challenge. On many occasions I am also reminded of the significance of this study while talking to parents of newly diagnosed autistic children at our center and seeing the tears of frustration, anger, and sorrow over what they perceive to be a lost child. I also talk to parents who are frustrated over the lack of services in our public schools. I talk to parents who have lost friends, lost marriages, and lost contact with extended family members because of stress and embarrassment. The dramatic and steady rise in the cases of autism, whether from better diagnostic tools, weaker immune systems, or more toxins in our environment, emphasizes the need to better understand the experiences and implications of living with autism so that

professionals and the community can offer the support these families so desperately need. Without a deep understanding of the implications of living with an autistic child and providing a framework from which a clear understanding can be interpreted, I fear a lost generation of children and broken homes where the need for a supportive, complete family is most essential. Families must learn the coping mechanisms used to adjust to stressful day-to-day living with autism. This study will hopefully provide insight to the various and perhaps unique coping mechanisms used by families affected by autism, knowledge that will be of educational value.

The inability, ignorance, or the lack of conviction to equal rights for all by the federal government to pass laws ensuring that insurance companies pay for the treatment of autism adds the stress of huge financial burdens to families with an autistic child. The cost of a behavioral therapy program, the only type of treatment with documented success, now exceeds \$30,000, with no help from insurance companies, or governmental agencies. Education, awareness, and treatment are key.

How do families learn to cope with the myriad of non-normative stress that permeates the entire family structure? What is it like to live in an autistic family? Although relevant information will be discussed in the Literature Review these questions remain unanswered, thus giving purpose to a rich descriptive, qualitative study using first hand accounts of the experience as data.

Chapter II: Review of the Literature

Intent of Chapter II

The literature review will provide a detailed account of the current information available on diagnostic procedures for autism, family stressors caused by an autistic child in the family, the implication of those stressors, and family systems theory as it relates to autism. Chapter II also investigates the limited body of knowledge on coping strategies, and resources a family affected by autism might use. Chapter II identifies the impairments of autism and details how researchers have used this information to create a plethora of rating and screening tools for diagnostic purposes. This knowledge is invaluable and supplies much needed background toward the understanding of the family and autism. The intent of the literature review is to provide background knowledge on the above mentioned aspects of autism so as to allow for deeper probing of the first hand experiences by the researcher and to provide educational material to the reader. This chapter will also build a framework, and foundation for the study to demonstrate the gaps in the literature that the study is addressing. As stated earlier, the intent of this study is to provide a better understanding of autism and the family through rich, deep description that only qualitative research can provide.

Introduction

The review of the literature on autism, and its effects on family will be done on three levels. First, a review of the current literature on autism and the core set of impairments will present a diagnostic system and a detailed outline of

characteristics that may be found in a child with autism. This section also includes reviews on screening tools, rating scales, and diagnostic interviews.

Second, a review of the current literature on family stress caused by autism, and the family's reaction to the stressors is presented. Resources, or lack of resources, coping strategies, family attributes, and perceptions will be reviewed as reactions, both positive and negative, that families display per studies related to this study.

Third, a review of family stress theory and family systems theory as it pertains to the interface of autism and the family will be offered as a theoretical framework of family stress and adaptation. The McCubbins, expanding on Hill's original ABCX Model, which focused upon the stressor, the family's resistance resources, and the family's appraisal of the stressor event, introduced the Double ABCX Model in 1981 (Figley, 1989). The expansions are displayed (see p. 49) in the Typology Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1989) which adds post-crisis variables in an effort to describe: (a) the additional life stressors and changes that may influence the family's ability to achieve adaptation; (b) the critical psychological, family, and social factors that families call upon and use in adaptation; (c) the processes families engage in to achieve satisfactory adaptation; and (d) the outcome of these family efforts. Although no models were found specifically pertaining to autism, the Double ABCX model does provide a framework for serious illness and/or chronic illness. A review of how autism and the family system interact discusses the family system as a whole, the parent-child subsystems, the sibling subsystem, as

well as the marital relationship. We now understand more and more that consideration must be given to the family system in planning interventions with autistic children (Bristol, 1985).

Autism: The core set of impairments and diagnosis.

Core Impairments

As stated earlier, autism is a biologically caused mental disorder appearing early in life and, usually, persisting in some form throughout life. The disorder can appear in many different forms. Some autistic individuals will be verbal, while others are mute; some will have normal intelligence, while others will have subnormal intelligence. All individuals with autism, however, will have in common three serious impairments involving their social interaction, their ability to communicate, and their patterns of behavior.

This core set of impairments is defined in a book of diagnostic criteria for mental disorders, *The Diagnostic and Statistical Manual of Mental Disorders*, which is published by the American Psychiatric Association (1994), and is commonly known as DSM-IV. The majority of health professionals recognize the diagnostic system in this book. According to the DSM-IV, to be diagnosed as having Autistic Disorder, an individual must have a minimum of 6 of the 12 problems listed below, and the onset of these problems must be prior to three years of age.

Impairment in social interaction due to autism is evident if an individual has two, or more of the following problems:

- Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate

social interaction.

- Failure to develop peer relationships appropriate to developmental level.
- A lack of spontaneous seeking to share enjoyment, interests, or achievement with other people.
- Lack of social or emotional reciprocity.

Impairment in communication due to autism is evident if an individual has at least two of the following problems:

- Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime).
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain conversation with others.
- Stereotyped and repetitive use of language or idiosyncratic language.
- Lack of varied, spontaneous make-believe play, or social imitative play appropriate to developmental level.

Impairments in patterns of behavior due to autism is evident if an individual has at least two of the following problems:

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interests which are abnormal in either intensity or focus.
- Apparently inflexible adherence to specific, non-functional routines or rituals.

- Stereotyped and repetitive motor mannerisms.
- Persistent preoccupation with parts of objects (pp.70-71).

In addition to the three core areas of impairment required for diagnosis of autism, the DSM-IV outlines a number of other characteristics that may be found in a child with autism, including:

Mental retardation.

Uneven profile of cognitive skills.

Language comprehension less than vocabulary suggests.

Hyperactivity.

Short attention span.

Impulsivity.

Self-injurious behaviors (e.g.: head banging; or finger, hand, or wrist biting).

Temper tantrums.

High threshold for pain.

Exaggerated reactions to lights and odors.

Fascination with certain stimuli.

Abnormalities in eating (e.g.: diet limited to a few foods, or eating inedible substances).

Sleep disorders.

Giggling or weeping for no apparent reason.

No emotion when it is warranted.

Lack of fear or excessive fear.

Depression (in adolescents who are aware of their disorder) (APA, 1994, pp. 67-68).

Diagnosis: Why the delay?

In a survey of parents of 128 children with autism Vostanis, Smith, Chung, & Corbett (1994) found that, although parents had suspected that something was wrong with their child's development at an average age of 17 months, the average age for the diagnosis of autism at the first referral was 44 months (42% of the sample). The average age for the diagnosis of the rest, i.e. children who needed at least one more professional assessment, was 82 months. Such delays in diagnosis have serious effects on children and their families as well as on the provision of clinical and educational resources.

There are many reasons why the proper diagnosis of autism is delayed for so long after the child's birth. Often, especially for first time parents, nothing is suspected at first, this is simply a beautiful child, perhaps quieter and less active than other babies, or perhaps more difficult. The children may show precocious talents for music or puzzles (Trepagnier, 1999), confusing the parents' judgment abilities. Also, the child with autism is not readily identifiable as handicapped by physical appearance (Sanders & Morgan, 1997).

Medically, the reasons are two fold. First, most medical doctors, i.e. pediatricians and neurologists, who see the child first when something is noticed by the parent as abnormal in their child's behavior, know very little about autism and the treatment options available (Caramagno, 1992). Second, those that do follow a regimented diagnosis procedure, usually without the input from a

clinical psychologist familiar with autism. The following medical tests are recommended before a diagnosis of autism is reached (Caramagno, 1992): a complete family history; history of pregnancy and birth; child's medical history; a detailed physical examination; a general, age appropriate medical and neurodevelopmental examination; a laboratory work-up, including a chromosomal analysis, an MRI or CAT scan, a cerebral spinal fluid examination, an auditory brain stem response, an ophthalmological examination, a hearing test, a blood test (for phenylalanine, pyruvic acid, and evidence of herpes infection), and a 24-hour urine examination for a metabolic screen and for the level of uric acid and calcium. Testing may take many months or years before parents learn their child has the disorder of autism. When and if they receive the proper diagnosis little advice is given as to treatment because as a medical doctor they can offer no medication that cures autism. The medical doctor may only be able to prescribe medications that prohibit bad behavior, such as Prozac or Zoloft, both anti-depressants. Few medical doctors recommend a clinical psychologist familiar with autism that will in turn recommend behavioral intervention. Yet children who receive early intervention tend to have better communication skills and fewer out-of-control behaviors, and parents of these children often have a greater understanding and acceptance of their child's disorder (Caramagno, 1992).

Another reason for improper or late diagnosis of autism is labeling. Autistic disorders according to the DSM-IV (APA, 1994) fall into the category of Pervasive Developmental Disorder (PDD) along with Rett's Disorder, Asperger's

Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Classified. The last category is used to classify atypical cases of autism that do not meet all the previously discussed criteria for autism because of the late onset and atypical symptomology. This label is used extensively, seemingly to avoid the word “autism.” A number of psychologists and psychiatrists have been debating whether or not Pervasive Developmental Disorder is a useful term. Some say the term is “an inappropriate and uninformative term that does not take advantage of the hard-won public awareness of autism” (Happé & Frith, 1991, p. 1167).

Gillberg (1991) opposes the use of the term PDD on the grounds that those that are labeled PDD, rather than autistic, may be deprived of their lawful rights because few people are aware that PDD indicates a serious mental disorder as compared with the number who understand what autism implies. The President of the Autism Society of America argues that those diagnosed as having PDD, instead of autism, may be denied their lawful rights: “Autism was recently added to the list of handicapped conditions in the federal laws mandating special education. PDD does not have this status” (Changes requested in DSM-IV, 1991). On the other hand, some professionals prefer to keep the term PDD, arguing that changing the term would involve considerable cost in terms of educating parents, service agencies, and other professionals (Volkmar & Cohen, 1991). Unfortunately, the professional debate over various terms for this condition and their inconsistent use only adds to the confusion of parents already bewildered by the perplexing behaviors of their child.

There are many adverse implications of a late diagnosis of autism, which include (Konstantareas, 1990):

1. Not providing a diagnosis for the autistic child makes the challenge of understanding the problem even more difficult and puzzling to the family. In view of the severe, and at times bizarre, characteristics of autistic children, if parents were to perceive the child's behaviors as reflective of parental or family pathology, it may frighten and puzzle other family members. A study by Mary Konstantareas (1990) indicated that even when parents were explicitly absolved of the responsibility of causation, they insist on self-blaming for things they objectively understand that they could not help.
2. Attributing the child's pathology to parents and siblings might result in guilt-induction, with its attributes of shame, remorse, and self-hatred manifesting themselves in other family members. Delay in diagnosis, thus a delay in understanding the pathology could result in confusion, hostility, and avoidance of the autistic child by the other family members.
3. A late diagnosis would prevent a speedy access to the appropriate interventions. These interventions, i.e. early behavioral treatment, are far more effective when they begin early (Lovaas, 1987).

4. Preventing access to community resources such as respite care, special needs workers, summer camps, athletic, and other community facilities that provide services for autistic children and their families is another negative effect of a late or no diagnosis.
5. Another drawback appears to be the tendency of parents to adopt corrective strategies of their own to change their parenting styles. Parents may become extremely permissive towards their autistic child, unknowingly rewarding the child for the very behaviors they wish never existed.
6. Useful information on medications, ongoing etiological factors and treatment innovations concerning autism is not given due to the lack of proper diagnosis. Failing to identify the problem deprives the family of access to the resources they require to cope with the catastrophic effects of having an autistic child.

There is great diversity in opinion regarding the effects of diagnosis of autism on the family. After an extensive literature review and study, Norton and Drew (1994) summarize by saying, "Very limited research exists on the effect of disabilities in general, with almost none in the field of autism. This strongly indicates the need for further systematic study on the effects of a diagnosis of autism on marital and family relations" (p.73).

Diagnostic and Assessment Instruments

In addition to greater awareness among professionals (i.e. medical doctors and psychologists), and the development of comprehensive services, screening for early signs and symptoms of autism could facilitate early detection. The following instruments are used by educators, clinicians, and researchers to assess children suspected of, or previously diagnosed with, a pervasive developmental disorder. Both screening and rating instruments for detection and severity of autism will be reviewed in the following sections.

Screening Instruments

The *Autism Diagnostic Interview-Revised (ADI-R)* is a semi-structured, investigator-based interview for caregivers of children and adults for whom autism or pervasive developmental disorders is a possible diagnosis. Studies were conducted by Lord, Rutter, and LeCouteur (1994) to assess the psychometric properties of the ADI-R. Reliability was tested among 10 autistic (mean age 48.9 months) and 10 mentally handicapped or language-impaired children (mean age 50.1 months), and validity was tested among an additional 15 autistic and 15 non-autistic children. Results indicated the ADI-R was a reliable and valid instrument for diagnosing autism in preschool children. Inter-rater reliability and internal consistency were good, and inter-class correlations were very high. A standard diagnostic interview is conducted at home or in a clinic. The ADI-R takes several hours to administer and score and determines whether or not an individual meets the Diagnostic and Statistical Manual of Mental

Disorders (3rd ed., revised) criteria for autism. The authors of the ADI-R plan to update the scoring procedure so it reflects DSM-IV criteria.

The *Prelinguistic Autism Diagnostic Observation Schedule (PL-ADOS)* (DiLavore, Lord, & Rutter, 1995) is a semi-structured observation scale for diagnosing children who are not yet using phrase speech and who are suspected of having autism. The scale is administered to the child with the help of a parent. This instrument provides an opportunity to observe specific aspects of the child's social behavior, such as joint attention, imitation, and sharing of affect with the examiner and parent. PL-ADOS scores are reported to discriminate between children with autism and children with nonautistic developmental disabilities. The resulting diagnostic algorithm is theoretically linked to diagnostic constructs associated with International Classification of Diseases (10th revision) and DSM-IV criteria for autism.

The *Checklist for Autism in Toddlers (CHAT)* (Baron-Cohen, Allen, & Gillberg, 1992) is based on information by the parents (9 items) and observations by the clinician (5 items). The features at 18 months, which predict the diagnosis of autism, include the absence of five aspects of functioning, i.e. pretend play, social interest, social play, protodeclarative pointing, and joint attention. The CHAT has been developed and tested in 91 toddlers at 18 and 30 months (41 siblings of children with autism and 51 controls). The initial findings are promising, but obviously need to be replicated in larger samples.

The *Infant Behavioral Summarized Evaluation (IBSE)* (Adrien, Barthelemy, Perrot, 1992) is designed for children of 6 months to 4 years. The IBSE is

composed of videotaped structured and spontaneous interaction, standardized activities, and free time for a total of 20 minutes. The evaluation includes 19 items measuring socialization, communication, adaptation to environmental situations, motility, emotional and instinctual reactions, and attention-perception. The IBSE has been found to be reliable and have satisfactory diagnostic validity in a comparison of autistic children, children with mental retardation, and normal controls.

Questionnaire Concerning Early Symptoms of Autism (Dahlgren & Gillberg, 1989) is a parent-rated questionnaire designed for children under the age of 2 years. The questionnaire's 130 items are rated on an analogue scale. The items describe early development, physical, and psychopathological symptoms of autism, as well as abnormalities of play, autistic aloneness, and the peculiarities of gaze and hearing.

Educational and behavioral treatment programs have been found to be successful in the management of some aspects of autism such as language, play skills, socialization, and behavior. There is now evidence that if an intervention starts early in life (before age 4) the benefits are not only short-term (Lovaas 1987), but also long lasting for autistic children and their families (McEachin, 1993). Early detection of the condition is essential in determining future outcome. Early screening can improve the currently low detection rates.

Rating scales for severity.

The *Childhood Autism Rating Scale (CARS)* (Schopler, Reicher, & Renner, 1986) is an observational measure of autistic behaviors with 15 scales rated

between 0 and 4 and is used in clinically referred children, and adolescents. Cut-off scores were established to distinguish between non-autistic, mildly-moderately, and severely autistic children. Although developed for all levels of autism, CARS has shown to be more appropriate for cases of autism of moderate severity.

The *ABC or Autism Behavior Checklist* (Krug, Arick, & Almond, 1980) is a rating scale that covers a broad age spectrum from 18 months to 35 years. The ABC measures 57 behaviors on five dimensions, which include sensory, relating, body and object use, language, and social aspects. The ABC has been widely used and found reliable for content, and to have concurrent and criterion-related validity (O'Brien G., 1992).

The *Ritvo-Freeman Real Life Rating Scale* (Freeman, Ritvo, Yokota, & Ritvo, 1986) aims at assessing the effect of treatment. The scale is based on observation and includes 47 types of behavior grouped in five scales of sensory-motor, social relationships, effectual responses, sensory responses, and language. The scale has proven to have satisfactory inter-rater reliability even with non-professional observers.

The tools for early diagnosis are present, but not widely known or used by the medical and psychological community. More research accompanied by awareness is needed. The dramatic rise in the disorder dictates that we place a priority on the diagnosis and treatment services for the children and their families afflicted with autism.

Obtaining the diagnosis changes the question from why is the child behaving like this – to what now. Without proper guidance many questions will arise. Is there a way to make it go away? How different would my child’s life be if not for autism? If he would have only continued to develop from the beautiful baby he was into the marvelous child he ought to be what would he be like? This kind of thinking is a sure recipe for pain (Trepagnier, 1999). The reality is, claims Trepagnier (1999, p.40), “most families with a newly diagnosed autistic child are embarking on a course that will demand their best efforts in all spheres – in thinking, planning, negotiating, empathizing with their child and the people around him, and managing their own emotions and behavior.”

Autism and Family Stressors

Literature on life stress indicates that among many potential threatening events and life circumstances, those characterized by their magnitude, intensity, duration, and unpredictability tend to constitute the most stressful situations (Rabkin & Struening, 1976). The conditions associated with parenting an autistic child appear to provide all the characteristics to produce life stress. Studies by Bristol and Schopler (1983), Holroyd and McArthur (1976), Wolfe (1989), and Sanders and Morgan (1997) report that parenting stress is significantly higher in parents of autistic children when compared to parents of children who have Down syndrome, mental retardation, or are normally developing. Furthermore, results from a study by Bouma and Schweitzer (1990) provide empirical support for the suggestion that chronic mental disorders such as autism contribute more to family stress than chronic physical disorders such as cystic fibrosis, even

though the latter is usually fatal. In addition, Sanders, and Morgan (1997) also found perception of family problems by parents of autistic children to be significantly more severe than the other groups. Further studies (Wolfe, 1989) have also indicated that parenting an autistic child may have an impact on the parents' health and well-being.

Sources of Stress and Their Implications

Introduction

The sources of family stress caused by autism are many, and vary depending on the severity of the behaviors. They are experienced quite differently from family to family, and by parents and siblings. Although there is very little systematic research on the impact of autistic children on their parents and siblings (Konstantareas, 1989), there is no doubt a substantial effect on the family as a system. "Further research on family stress is clearly required and a theoretical refinement appears in order" (Norton & Drew, 1994, p. 76). The following is a literature review on sources of stress and their implications, as we understand them today.

The sources of stress, per current literature, are extensive, but may be grouped into major categories, not considering the minor stressors which make up the category. The implications of the stressors upon family life may be falling short in detail, again leaving the reader without a reasonable understanding of what implications are caused by the stressor. For example, in the paragraph below, Piven, Chase, Landa, & Wzorek (1991) report that parenting a child with

autism has detrimental effects on marital relations. Fishman and Wolf (1991) talk about the lack of intimacy. The statements may be vague and effects may be left unexplored. Detrimental effects on marital relations could range from divorce, with one spouse completely separating themselves from the family, to arguments on who gets up with the child on sleepless nights. Also left out may be the pile-up, and escalation of stressors that can result in separation (mentally or physically), or divorce. Non-descriptive, quantitative reports are the rule rather than the exception. This study will provide detailed data on the stressors these families experience, and the effect of stressor pile-up on family life.

Literature on sources and implications of stress

Parenting a child with autism has been shown to have detrimental effects on marital relations (Piven, Chase, Landa, & Wzorek, 1991). In a study by Fishman and Wolf (1991), mothers of children with autism scored significantly lower on total intimacy than mothers of children with Down syndrome or mothers of normally developing children, and significantly lower on compatibility with their spouse. The second factor, the study suggests, may be a reflection of the lack of recreation time available for each other and for the family because of the heavy burden of parenting, especially when respite care and other services are not available. Featherstone (1980) reports that the diagnosis of a disability can produce powerful emotions in both partners as a symbol of shared failure. He also concludes that the disability can reshape the organization of the family and can create fertile ground for conflict. Sanders and Morgan (1997) report that

families with an autistic child experience greater stress associated with finding the time and energy to make effective use of their free time.

Mothers and fathers likely would have questioned their parenting skills and abilities for quite some time before receiving a diagnosis (Rodrigue, 1992), because bad behaviors induced by autism may have been perceived as a parenting flaw. This perception of parenting efficacy may cause the parents to change parenting behaviors, affecting the siblings of the autistic child. Parents may also modify their family planning, worrying about having more children with disabilities, and adding to the financial burden of caring for an autistic child.

Studies by Rodrigue (1992), and Plienis, Robbins, & Dunlap (1988) report concerns about the availability and adequacy of financial resources. Parents in this study reported concerns about the financial costs incurred secondary to raising an autistic child and whether family income was sufficient to cover the child's current and future expenses (e.g., special schooling, therapy, medical services). Unlike developmentally normal children, who usually achieve financial independence, most children with autism require long-term financial resources. Most autistic children will remain dependent all their lives (Bouma & Schweitzer, 1990). Mothers of autistic children report that the caretaker burden is theirs (Sanders & Morgan, 1997), thus creating one-income households, adding further financial strain.

The stress of living with an autistic individual can affect the psychological well being of a family as well as generate conflicts among them. The difficulties

produced by autism, however, go beyond the family, in that families with autistic children have to interact with the outside world. Gray (1993) reports that as a consequence of the behaviors of autism, many parents tend to isolate themselves and their families from social contact with the outside world, and furthermore, the social life that families do manage to maintain are restricted to their extended family, a few friends who can deal with their child's condition, or other families with autistic children. Rodrigue (1992) reports patterns of social withdrawal, less contact with extended family, changes in friends, fewer husband-wife activities, decreased church attendance, and fewer visits with neighbors. Haefele and Henggler (1983) reflect this view, noting that the autistic child's unpredictable behavior may make it difficult to take him or her out in public, thereby limiting family outings. As a result of a study done by Sanders and Morgan (1997), they conclude that the strong feelings the parents of autistic children have about their children's negative characteristics place them at higher risk for withdrawing into the family, and making less use of social supports and outside activities that may alleviate stress. In the case of autism, because there are no physical differences, social stigma comes from ignorance; it ranges from stares and hostile glances to social service agencies reporting physical abuse of a child who will not stop crying or has bruises from self-injurious behavior (Lyle, 1992).

Some of the most disturbing behaviors of individuals with autism involve their being aggressive toward themselves or others. A very minor event (e.g. saying "I know") can set some children with autism into wild, screaming,

pinching, biting, and/or throwing frenzies, which can last for hours (Holmes & Carr, 1991). Sometimes, however, there appears to be no reason for the behavior, and little parents can do once it begins, other than wait for the child to fatigue (Christopher & Christopher, 1989). Self-abusive behavior, according to Konstantareas (1989), turned out to be the best predictor of stress for parents. “This,” says Konstantareas (1989, p. 468), “is not surprising since self-abusive children are not only more visibly disturbed, they may also inflict damage to their bodies.” Parents of such children reported feeling helpless, overwhelmed, and frightened by their child’s behavior. Furthermore, these parents frequently interpreted self-abusive behavior as a reflection of their child’s inability to relate appropriately to them, their own poor parenting and management skills, and their general ineffectiveness in parenting them (Konstantareas, 1989).

Parents often fantasize about how their child will look or act, projecting their own hopes and dreams onto their child. When parents learn their child has autism and come to accept the diagnosis and its implications, they begin the process of mourning. Burke, Hainsworth, Eakes, & Lindgren (1992) refer to this type of mourning as chronic sorrow. Pauline Boss (1999) refers to this type of mourning as ambiguous loss, and maintains it is the most devastating of all the stressors related to chronic illness because it remains unclear, indeterminate, and life-long. As developmental milestones are not reached as anticipated the severity of mourning increases. The ambiguity complicates the mourning process; it feels like a loss, but it is not really a loss. We see the abstractness of not being certain about a person’s absence or presence. Preoccupation with the

constant grief can plummet families into depression, anxiety, and cause somatic illness (Boss, 1999).

Norton and Drew (1994) emphasize communication as a major concern. There may be no mode of communication. The child is unresponsive verbally and non-verbally, and may be trapped in his/her world. The child may not be able to recognize facial expressions, body language, or emotions. The child cannot conceive abstract thinking, only able to relate to concrete thoughts or ideas. He/she may experience repetitive speech, frequent irrelevant remarks, and echolalia. They may not be able to sustain a conversation, even if speech is adequate. Usually there is no spontaneous communication; it must be prompted.

Autistic children often reject attempts to be held, cuddled, or kissed (Pingree, 1984). Researchers report of babies that were too good, who seemed to require little food, and no holding. On the other end of the spectrum is the baby who cries inconsolably for hours. Either of these descriptions can be portrayals of an individual with autism, and either behavior creates difficulty in bonding for the parent (Moreno and Donnellan, 1991). The question, how long will a parent persevere when all attempts of love and attention are rejected?

Erratic sleep patterns plague families of children with autism, who may only sleep 3-4 hours a night. Parents, of course, find it difficult to remain alert in performing their daily activities. This type of sleep pattern and its related behaviors present a relentless drain on family members' physical and emotional resources. Parents may rotate nights to alleviate total sleep deprivation (Norton & Drew, 1994). Pingree (1984) best sums up the experience when she describes

sleep disruption by her autistic son, “half sleeping in the bedroom above, we hear the light switch being flicked on and off, on and off, by his tiny hand” (p. 330). This type of sleep pattern and its related behavior create an enormous disruption to family routine and present a relentless drain on family members’ physical and emotional resources (Hardman, Drew, Egan, & Wolf, 1993).

Children with autism are often described in terms of knowing more than their age-mates but not exhibiting appropriate verbal or social skills for a child that age. An example is given of a daughter, who at age seven, knew the definition of words such as “perigee” and “apogee,” but could not communicate her daily needs (Moreno & Donnellan, 1991). Pingree (1983) tells a story of a young child who could sing a complicated song after hearing it only once, yet could not ask for a glass of milk. The same child could open complicated locks, but could not use a fork to feed himself. This wide divergence in ability promotes a much greater expectation level than the child is able to deliver and leads to high levels of frustration and anxiety for both parents and child (Norton & Drew, 1994).

Individuals with autism seem to prefer constancy and maintaining the same routines, and they can become attached to objects. The slightest change in routine can cause serious difficulty for the families of children with autism. Such change can produce screaming and crying that lasts for hours (Norton & Drew, 1994). Accompanying the desire for sameness comes a tendency to be continually frightened of harmless things, while seemingly oblivious to actual threats and dangers. The difficulties in coping with change and recognizing danger play

major roles in family decisions regarding relocations and job advancements (Moreno and Donnellan, 1991).

Sanders and Morgan (1997) report that mothers and fathers of autistic children both showed pessimism about the future of their children, especially about problems that may arise when their children reach adulthood. This source of despair for the parent is often present throughout the life of the child, but may intensify as parents reflect on their own mortality and the effects that their deaths may have on the autistic child (Wickler, 1981). Family planning regarding who will take care of the child after the deaths of the parents can be a stressful activity and, potentially, may cause family conflict (Sanders & Morgan, 1997). Studies by Koegel (1992), and Holroyd & McArthur (1976), also reflect the same conclusions revealing parental concerns about the child's dependency, lack of current or potential independence, and the concern with the long-term burden of parenting the autistic child.

Sibling stress and implications

There appear to be both positive and negative effects on siblings of living with a child with autism. A recent study by Gold (1993) of MacMaster University compared the siblings of autistic boys to those of a control group and found that brothers and sisters of boys with autism scored significantly higher on depression than the comparison group, but not on problems of social adjustment. Children with a sibling with autism appeared to be more embarrassed in the presence of other children and peers than children in other groups, such as mentally retarded or Downs syndrome children, most likely because of the

bizarre behaviors (Roeyers & Mycke, 1995). This also reflects the findings by Bagenholm and Gillberg (1991) who reported on child interviews. Howlin and Yates (1990) also mentioned that most of the problems brought up during the support group sessions had to do with peers and their reactions.

In one of the few comparative investigations of autistic children, DeMyer (1979) studied 59 brothers and sisters of autistic children and 67 siblings of normal controls. She found more children in the autistic group (30%) reported feelings of being neglected; 18% reported worries and anxieties associated with the condition; and 15% of parents reported problems of toileting and eating. McHale, Sloan, and Simeonsson (1986) report that many children feel they have not received the same amount of attention from their parents as the impaired child, and express feelings of unfair treatment, with their sibling able to get away with more than they could ever do. They also report difficulties associated with having to do more household tasks, having to physically care for their sibling, or to carry out other chores because of the greater amount of time and attention required by the autistic sibling. Sorenson (1993), a proponent of conducting studies through the child's perspective, warns against relying on siblings' assistance to the degree that it negatively affects inter-sibling relationships.

August, Stewart, and Tsai (1983) report a higher incidence of learning problems in siblings of autistic children. Rates of language-related problems, such as early speech delays, or later reading and spelling problems, are significantly higher in the siblings of autistic children than in other families.

Amongst other types of difficulties reported in normal siblings are feelings of guilt and fears that they may somehow be responsible for the condition. Identity problems have also been noted, with the normal child having secret fears that he or she, too, might be affected in some way. Psychological stress is reported frequently. Siblings may feel the need to over-achieve or make up for the limitations of the autistic child. They may feel under pressure to provide for the needs of their autistic sibling, as the parents grow older and eventually deceased (Howlin, 1988).

A study done at the University of North Carolina, reported that siblings of people with autism did not need any special intervention. The belief was that this was perhaps due to a positive self-concept and academic achievement, which was a result of improved provision of services for the autistic brother or sister and their families (Mates, 1990). The study found no differences between siblings of different groups on measures of self-concept, academic achievement, or home or school adjustments.

Many studies (Mates, 1990; McHale, 1986; McHale, 1984; Featherstone, 1982; Roeyers & Mycke, 1995) indicate that sibling adjustment to stress depends on a variety of circumstances. Family relationships, marital satisfaction, the parental ability to communicate to the normal siblings about the impairment, and the severity of the impairment all play a role in determining sibling well-being. McHale (1986) suggests that siblings in larger families seem to adjust better than siblings in smaller ones. McHale found that larger family size was associated with less embarrassment and fewer feelings of burdens for siblings.

Coping Strategies and Resources

Introduction

Resources, as defined by Webster, are things such as money, support, relief, stratagem, and means that lie ready for use or can be drawn upon for aid. Coping, as defined by Lazarus and Folkman (1984), are constantly changing cognitive and behavioral efforts to manage internal and/or external demands that are appraised as taxing or exceeding the individual's resources. All families are individual systems with differing compositions, values, and ambitions. All families are characterized by idiosyncratic strengths, resources, and coping abilities. Autism, however, is such a distinctive, and difficult disability that some generalities can be derived.

Family Competence and Confidence

Children with autism do well when their families acquire skills and knowledge along with the confidence that they can use these competencies to solve problems, and create desirable and productive environments for their child's development. As families do well so does their autistic child (Fox, Dunlap, & Philbrick, 1997; Robbins, Dunlap, & Plienis, 1991). Because families are often their autistic child's lifelong and most influential resource, there is nobody more important than the family in shaping the child's life and, thus, nobody who is better able to utilize relevant competencies on the child's behalf (Bailey, Simeonsson, & Winton, 1986). Among the competencies to consider are interactional skills, including those used in instruction, behavioral support, and the development of functional communication and language. Problem solving

skills and knowledge of functional assessment are similarly valuable (Dunst, 1985). Having the skills needed to interact pleasantly, productively, and to solve problems successfully is crucial not only among family members but also because there is an ongoing need for families to share these skills with other caregivers, teachers, friends, and support providers (Dunlap & Fox, 1999). In the researchers' opinion, further inquiry is needed to uncover what problem solving skills parents with an autistic child use.

Possessing the skills to promote the development of one's child is important, but insufficient. It is also necessary to be familiar with the services that are available and to know how they can be accessed (Sullivan, 1997). Families must know where to find information about services and how to act as advocates for the autistic child and family. Families that include autistic children who are doing well are usually adept at interacting with the system, forming useful affiliations, and making use of those resources that fit within a well-conceived support plan (Fox, Dunlap, & Philbrick, 1997; Robbins, Dunlap, & Plienis, 1991; Sullivan, 1997).

Studies by Koegel & Koegel (1990), and Koegel, Koegel & Parks (1990) suggest that reducing the child's behavior problems and teaching more independent living skills to the child, either directly or indirectly via parent training and/or training in self-management holds the potential for reducing stress for the parents and the family as a whole. Existing data collected from time activity diaries kept by parents of children with autism by Koegel, Schreibman, Britten, Burke, and O'Neill (1982) support the 1990 studies reporting that while

parents were initially quite low on time spent in recreational and leisure activities, those parents who were trained to work with their children in reducing problem behaviors and dependency subsequently reported significantly more time in recreational and leisure activities than did the parents who had not been trained to work with their children. Parent and sibling training need to begin early and continue throughout the different phases of the autistic child's life to minimize negative family impact (Norton & Drew, 1994).

Support Groups, Respite Care, and Financial Matters

Participation in a support group such as a local chapter of the Autism Society of America, would allow association with other parents of autistic children and foster cooperative efforts directed toward development of needed family programs (Sanders & Morgan, 1997). Another group, which offers family-centered supports addressing the needs of young children with autism, is the Individualized Support Project (ISP) (Dunlap & Fox, 1999).

Relief from the constant demands of a child with autism, or respite care, is essential to the physical, and emotional well being of parents (Norton & Drew, 1994). Respite care allows parents time away from the demands of their child to pursue recreational, cultural, and intellectual interests (Sanders & Morgan, 1997). Respite can come in the form of formal or informal care. Informal care is usually provided by friends and family, whereas formal care is that which is paid for, usually by a social agency (Norton & Drew, 1994).

Another study by Sharpley, Bitsika, and Efremidis (1997), which emphasizes the need for respite care, was significant on two levels. There were

consistently lower scores on depression, anxiety, daily level of stress, and frequency of being stretched beyond their limits for parents who had access to family members for childcare than those parents with no such access. These parents also reported higher levels of confidence in handling their child's major difficulties. Furthermore, there was a significant main effect according to the level of understanding, which parents felt that their immediate family member had of the child's problem. Parents who believed that family members giving assistance had a clear understanding of the child's difficulties and needs were also less anxious, depressed, and had higher levels of confidence in their own abilities to handle their child's difficulties. As stated earlier, training is essential for parents and siblings. This study seems to suggest that training for extended family members, who are willing, adds another positive dimension to both respite and training.

Financial planning for the years beyond which the autistic child is at home must begin early (Norton & Drew, 1994). Such a youngster need not remain at home forever and be considered a burden to the family. His or her capacities need to be developed through education and behavior training to allow the fullest life possible (Norton & Drew, 1994). Specialized education and/or training can be extremely expensive and may require long-term financial resources throughout adulthood (Rodrique, 1992). Proper financial planning, including wills and trusts, should be in place long before they are needed (Sanders & Morgan, 1997). Also very important for parents is to become familiar with Social Security requirements for a child to be eligible for Supplemental

Social Security Income (SSI) and Medicaid, if it is necessary (Norton & Drew, 1994).

Spousal Support, and Family-Based Intervention

Studies by Milgram and Atzil (1988), Konstantareas (1989), and Konstantareas, Homatidis, and Plowright (1992) all report that parental sharing in the rearing of an autistic child will reduce stress for both parents. The studies also agree that the parenting burdens are not shared equally between mother and father, with mothers assuming most of the responsibility. Konstantareas (1989) reports the types of support sought, by mothers of autistic children, from their spouses. Mothers wished from their spouses: (a) to provide them with some relief from caring for the autistic child; (b) to assume more responsibility in disciplining; (c) to have husbands helping spontaneously with daily chores and responsibilities rather than having to be asked. The quantitative studies report general categories; one intent of this study was to allow for fertile, descriptive details of support sought by spouses.

Results from a study by Bouma and Schweitzer (1990) highlight the need for family-based intervention programs specifically tailored to suit the psychological or physical nature of the child's disorder. Intervention programs for the families of autistic children not only should help to deal with the despair, shame, and isolation that may be experienced, but they also could lobby for an increased understanding by the general public in the form of educational programs or the distribution of educational materials.

Normality, Habituation, and Action

Research on the families of autistic children by Gray (1993) focuses on the strategies by which families cope with the effects of stigma in order to normalize their encounters with the outside world. The emphasis here appears to be on living as normal a life as possible while avoiding those individuals who will not cooperate in negotiating a definition of the situation as normal. In addition, parents are also concerned with avoiding excessive involvement with organizations that service the needs of the disabled so as to avoid over identification as a family with a disability. West (1986) argues that most families use a strategy of selective disclosure. In this strategy the presence of the disorder is only disclosed to those who are sympathetic, to those who may need to know, and to those who are likely to find out anyway.

One of the basic coping strategies for parents of an autistic child is simple habituating or becoming accustomed to their behaviors (Hart, 1989). After a period of time, the abnormal becomes the norm, which makes the behavior easier to overlook.

Often parents of children with autism mount vigorous campaigns to improve educational services, try new treatments, and to provide social interaction opportunities. Many work on improving services and opportunities not just for their own child, but also for other autistic children. Action is a coping mechanism that allows parents some piece of mind, knowing they are doing all they can for their child, as well as others (Trepagnier, 1999).

Sibling Adjustment

One of the most powerful influences on sibling adjustment appears to be the ability of parents to convey positive attitudes about the impaired child. Several studies have shown if the parents demonstrate acceptance of the autistic child the child's siblings react similarly and if the parents communicate openly about the impairment, the siblings understand the condition and create a positive adjustment to the condition (McHale, Sloan, & Simeonsson, 1986). The use of sibling groups has also been effective in that these provide siblings with peers with whom they can talk about their brother or sister with autism (Gold, 1993).

Howlin (1988) suggests a number of ways in which to minimize the effects of autism on siblings. Parents can increase other family interactions, deliberately setting aside short periods of time for the exclusive benefit of the other children, either by using respite care or dividing the time between parents. Providing privacy can be of vital importance both for entertaining friends, keeping valuables safe, and doing homework. A simple lock on their bedroom door can prove an effective solution. Parents should not rely heavily on support, both physically and mentally, from their other children. Too much babysitting of, and over-involvement with the autistic sibling can cause resentment of the autistic sibling. Also important is that parents have certain rules of behavior for the autistic child as well as the others and to ensure that these are kept to as far as possible. If the autistic child is able to do routine chores, no matter how simple, it can help in the interests of equality.

Children with autistic siblings may also need some help to come to terms with their own, often confused and ambivalent, feelings of love, protection, guilt, and anger, and they need to be reassured that such feelings are both natural and understandable, not a reason to be ashamed (McHale, Sloan, & Simeonsson, 1984; Carr, 1985). Several studies have reported the use of siblings as therapists for autistic children (Howlin, 1988; Mchale, Simeonsson, & Sloan, 1984). They have proven effective both in reducing behaviors and increasing skills, and their involvement in therapy is clearly beneficial for all concerned. As well as this benefiting the autistic child, it also helps boost the siblings' self-esteem (Lobato, 1983).

Howlin (1988) concludes his study by telling parents the most important fact to remember is that normal family life is by no means problem free. Quarrels, violent battles, temporary enmities, are all part of the day-to-day interactions between brothers and sisters. The presence of an autistic child is most unlikely to be the sole cause of such problems, although, of course, it may exacerbate difficulties from time to time. Rutter (1981) reports that it is also important to be aware that, on the whole, normal children are remarkably resilient to many early adversities. His follow-up studies indicate that, although some siblings show lasting problems, most show surprisingly few major after-effects.

Family Stress and Adaptation

Introduction

As noted earlier, autistic behaviors and their implications do not happen in a vacuum, they happen in a family system, therefore affecting family life. At the present time there is no generally accepted conceptual framework that guides research efforts in studying healthy family adaptation to autistic children (Bristol, 1987; Norton & Drew, 1994). Systems that are impacted by the interaction with the family include the extended family, friends, the neighborhood, the school, and other service agencies.

The system affected most directly by the presence of an autistic child, however, is the immediate family. The effects are not limited to interactions directly involving the autistic child, but extend to other family interactions such as the relationship between the parents as well as the relationships between the parents and other children in the family. These relationships are reciprocal. The autistic child not only has effects on the family but the family has effects on the behavior and adjustment of the child (Morgan, 1988). A core principal of the family systems orientation is that any system functions as a whole, and its components are necessarily interdependent (Minuchin, 1985). The potential impact of an autistic child within the family goes beyond the effects on individual functioning, or dyadic relationships, perhaps altering the functioning of the family system as a whole, and changing the course of its development (Morgan, 1988).

Family Adjustment and Adaptation: The Model

Providing a framework for understanding stress, coping, resources, and adaptation will be helpful in understanding a family's adaptation to stress when presented with an autistic diagnosis for their child. It is apparent that no stressful event or stressor, including the presence, or care of an autistic child, invariably causes a family crisis (Bristol, 1987). Hill (1958) proposed a classic ABCX model of family stress in which the characteristics of the stressor event (A), the family's internal crisis-meeting resources (B), and the family's definition of the stressor (C) contribute to the prevention or precipitation of a family crisis (X).

To expand Hill's original ABCX model, McCubbin and Patterson (1983) proposed a Double ABCX or Family Adjustment and Adaptation Model. To the original ABCX model, the Double ABCX model adds the pile-up of other family stresses that make adaptation more difficult (aA): the social and psychological resources (bB) and coping strategies (BC) that the family uses in managing potential crisis situations; the meaning, or perception, the family assigns to the event (cC); and the range of both positive and negative outcomes.

The Double ABCX model may be useful in autistic family-based intervention for the following reasons, it: (a) addresses family stress in a chronically ill context (b) recognizes the social and contextual nature of adaptation over time (c) provides assessment of coping strategies and resources, and (d) addresses the possibility that healthy adaptation rather than pathology may characterize the family's response to stress.

Summary

Chapter II has provided information regarding the behaviors of autistic children, the stress caused by the behaviors, and the effects the stress may have on the family; however, *the thoughts, feelings, and emotions about family life with a child with autism are what are painfully absent in the current literature, a gap in the current literature that this study fills.* The data collected on the behaviors of autistic children are consistent with the American Psychiatric Association (1994) core set of impairments, and the various screening and rating instruments. The data collected on sources of family stress are also consistent with the findings referred to in Chapter II; however, the data do reveal more sources of stress not previously discussed in the literature. Coping strategies and resources researched in Chapter II, while producing an accurate but incomplete list, lack the description of inner growth experienced by the families of autistic children, and the adaptational process. This study provides rich and descriptive information on actual families effected by autism. The study gives first hand accounts of actual experiences, from which the data are derived. The study allows us to better understand, using lived experiences, what it is like to be a parent of an autistic child, and what that experience means.

Chapter III: Method

Research Design

Qualitative research, broadly defined, means “any kind of research that produces findings not arrived at by means of statistical procedures or other means of statistical quantification” (Strauss & Corbin, 1990, p. 17). Creswell (1998) defines qualitative research as “an inquiry process of understanding based on distinct methodological traditions that explore a social or human problem” (p. 15). The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. The view that reality is constructed by individuals in interaction with their social worlds is the key philosophical assumption upon which all of qualitative research types are based (Merriam & Simpson, 1995). Where quantitative researchers seek causal determination, prediction, and generalization of findings, qualitative researchers seek illumination, understanding, meaning, and extrapolation to similar situations. Qualitative research has an interpretive character, aimed at discovering the meaning events have for the individuals who experience them, and the interpretations of those meanings by the researcher (Patton, 1990). Eisner (1991), Lincoln and Guba (1985), and Patton (1990) all agree on features of qualitative research that support the previous statement. The following list represents a synthesis of these authors’ descriptions of qualitative research:

1. The researcher uses the natural setting as the source of data. The researcher attempts to use what Patton calls “empathetic neutrality” (1990, p. 55).
2. The researcher acts as the human instrument of data collection.
3. Qualitative research reports are descriptive, incorporating expressive language.
4. Qualitative research has an interpretive character, aimed at discovering the meaning the events have for the individuals who experience them, and the interpretations of those meanings by the researcher.

Qualitative research method using a phenomenological approach was employed in this study to better understand the phenomenon of living with an autistic child.

Sampling

Purposeful sampling (Patton, 1990) is a dominant strategy in qualitative research because it seeks information-rich cases, which can be studied in depth. The phenomenological approach further requires that all participants share the same experience. Such was the case with this study. The researcher is the executive director of the Autism Learning Center, which supplies behavioral therapy to autistic children in the Northern Virginia area. Because of the life experiences shared between the researcher and the families receiving services from ALC, access and confidential probing into sensitive issues, such as embarrassing behaviors and the physical state of their homes for research

purposes was accepted. Therefore, all 6 families chosen for this study provided rich information about being parents of autistic children and received services from the Autism Learning Center.

Criteria

The criteria for participation in this study were as follows: (a) the participants must be parents of an autistic child (b) who are in a two-parent family, and could supply first hand information about the experiences of living with an autistic child, and (c) were willing to participate in a study that would allow the researcher an interview and observation in their home, and (d) the child had a medical and/or clinical diagnosis of autism.

Access

The first step taken by the researcher, who is the executive director of ALC, to gain access was to make the families aware that a research project was going to take place, and that the study would hopefully involve the center in some capacity. The study, as it took shape, was explained to the parents in a series of parent meetings held at the center, to those who were interested. After a discussion with each family about the purpose of the study and time commitments, 6 sets of parents were asked to participate based on the above-mentioned criteria. All that were selected accepted and expressed a high level of comfort with the researcher due to shared life experiences and signed a letter of consent upon the initiation of the study ([See Appendix C](#)).

Epoche

Prior to the interview the researcher engaged in the Epoche ([See Appendix A](#)) process, so that to a significant degree, past associations, understandings, facts, and biases were set aside and did not color or direct the interview (Polkinghorne, 1989). Engaging in the Epoche process was also necessary during the interview.

Because of the researcher's life experience as a father of an autistic child, engaging in the Epoche process was difficult. During the drive to the participants' home the researcher would listen to classical rock to set a stage in his younger carefree years. These years were dwelled upon, recalling specific experiences with great detail. The mind was emptied, as well as possible, of present and future thoughts, and the researcher doggedly tried to sustain this state of consciousness during the interview/observation process. Of course, the researcher still listened with an empathetic, not judgmental ear.

Data Collection Techniques

The two prevailing forms of data collection techniques associated with qualitative inquiry are interviews and observation. Typically in the phenomenological investigation the long interview is the method through which data are collected on the topic and question. To give the study more depth, however, both interview and observation were used. The long interview allowed the interviewer to probe and explore within the predetermined inquiry areas and allowed for individual variations (Patton, 1990). The phenomenological interview involved an informal, interactive process and utilized open-ended

comments and questions (Moustakas, 1994). The interview began with a social conversation aimed at creating a relaxed atmosphere. Following this opening the researcher asked the participant to take a few moments to focus on an experience, and then to describe the experience fully. With the participant's consent, the interview was tape recorded, and then transcribed into Word documents. Recording had the advantage of capturing data more faithfully than written notes, and made it easier for the researcher to focus on the interview.

Observation was used in conjunction with the interview. Observational data are used for the purpose of description---of settings, activities, people, and the meanings of what is being observed from the perspective of the participants. Observation can also lead to deeper understanding than interviews alone, because it provides knowledge of the context in which the events occur, and may enable the researcher to see things that participants are not aware of or are unwilling to discuss (Patton, 1990). The unstructured observational strategy (Merriam & Simpson, 1995) employed in this study was to engage in limited interaction, intervening only when further clarification of actions was needed. Field notes were used to provide running descriptions of settings, people, activities, and sounds. As with the interviews, the observation notes were transcribed into Word documents.

Common characteristics

The participants shared many demographic characteristics that are typical of families that receive services from the Autism Learning Center. The researcher is not suggesting the autistic community as a whole equally shares these

characteristics. The researcher also realizes that some of these characteristics may limit the study as well as enhance it. The following are common traits shared by all participants in the current study:

1. Parents of an autistic child.
2. Families consist of 2 parent household (mother and father)
3. The autistic child receives behavioral therapy.
4. Parents and children are in good physical health.
5. Residents of Northern Virginia.
6. Parents have a college education.
7. Parents age ranges from 33 to 51.

More demographic information ([Table 1](#)) was collected to provide a much richer description of the participants, their families, and surroundings. The demographics included, (a) specific ages of all family members, (b) occupations of parents, (c) socio-economic status, (d) race, (e) use of family therapy, (f) location of extended family, and (g) use of respite care.

Setting of the Study

Both interviews and observations were conducted at the participants' home following the guidelines of qualitative research for data collection to take place in a natural setting. The researcher felt it important that all family members be present to allow total family interaction. The interview/observation times varied from 2 1/2 hours to 4 hours and took place on a given Saturday or Sunday at the participants' home. The interview/observations started on January 13th and continued through February 4th, 2001.

Flow of the home visit

Before the final agreement between the researcher and participants was concluded, and prior to the day of the interview, a detailed explanation of the study was given. All participants agreed that all family members would be present. This provided a setting for family members to interact with each other, including interactions between spouses, siblings, and between the parents and the siblings. After being assured of confidentiality, all participants agreed to audiotaping and observational note taking during the sessions.

The parents were interviewed together using an open-ended interview technique. That is to say, a guided interview ([See Appendix D](#)) was used allowing information to surface as the interviewee recalled it and/or allowing verbal spontaneous interaction between spouses to enrich experienced events or thoughts. This interview technique allowed the researcher the opportunity to probe, but also ensured all pertinent topics were covered.

Following the phenomenological interviewing guidelines (Moustakas, 1994), the researcher first generated conversation by asking the participants to describe yesterday as the day unfolded, and to supply as much detail as possible. This allowed for precise recall and the opportunity to discuss differences in the day between spouses. This general type of questioning promoted volunteering of information and created a comfort level for the participant due to its non-invasive nature. To enrich, and give life to the participants and their families the interview also included questions concerning demographics ([See Table 1](#)). Also included were probing questions about particular experiences that produced

emotions of joy, sorrow, anger, and embarrassment. Reactions to autistic behaviors in social settings were explored, as well as reactions from extended family about the diagnosis and acceptance of autism in their family. Other topics that were explored included: the best school experiences, and the worst, the use of support agencies, and what resources were available. The interview ended after giving the participants the opportunity to add anything that they may have forgotten, or to add to anything they thought the researcher might have omitted. Physical and mental observational note taking was done before, during, and after the interview process on family interaction, physical appearances of family, home behaviors of the autistic child, and family reactions to the behaviors. Such things as pets, toys, TV programs, and other relevant information were also noted.

Organization and Analysis of Data

Organizing a pile of raw data can be a daunting task. Computer software programs can now handle the mechanics of transcription, and sorting large quantities of qualitative data. Dragon Speak Preferred was used to transcribe the interview data directly into Word documents. The Word documents were then converted to Rich Text Format (RTF), and imported to NVivo, which enabled the analysis process. The writing of Chapter IV, Presentation of the Data, used a phenomenological model adapted from Moustakas (1994) ([See Appendix A](#)). The following is the sequential process used by the researcher: (a) the phenomenological analysis process began by regarding every statement in the interview, and every observational note as equal in value. The identification of

the relevant statements emerging from the raw data were coded as free nodes; (b) Horizontalizing of the data followed. This process deleted statements, and notes irrelevant to the topic as well as those that were repetitive, or overlapping. This left only the Horizons, which are the textural meanings, and invariant constituents of the phenomenon; (c) The Horizons, the meaning, or meaning units (Moustakas, 1994), were coded as tree nodes, with groupings of related statements coded under them as children or sibling nodes, further refining the reduction process; (d) The clustered themes, and meanings were used to develop the textural descriptions of the experience; (e) The researcher provided structural implications of the textural description; (f) Finally, the researcher constructed an overall description of the meaning, and the essence of the experience using an integration of textural descriptions, and structural descriptions.

Chapter IV: Presentation of Data

Introduction

As was mentioned in Chapter I, I am the father of an autistic child, and founder, and executive director of the Autism Learning Center, a non-profit center based in Northern Virginia. We provide intensive early intervention services to autistic children and their families. Autism is a highly emotional bond shared by afflicted families. The strong emotions experienced during these interviews, for me, were therapeutic, yet emotionally draining. Although I experience autism every day, and from time to time engage parents in conversation about specifics, I have never gathered complete pictures on how other families experience this disease. The families interviewed were very forthcoming, honest, and extremely generous with information, and all expressed the uniqueness of being able to fully express themselves to someone who could understand their plight. This was my distinct advantage in collecting data.

Many families shared common experiences, as the data will indicate, and although some physical characteristics, behaviors, and settings may be different, general thoughts, feelings, and emotions were constant. To reiterate, the thoughts, feelings, and emotions are what are painfully absent in the current literature, a gap that this study fills, thus adding to the current body of knowledge about the experience of living with an autistic child. Through the process of phenomenological reduction, the following pages tell the stories of 6 families with autistic children. Two families have only one child, 3 have 2

children, and 1 family has 6 children. Drawing from different family compositions, in this manner enhanced the data. Separate family stories were told using individual textural and individual structural descriptions of life experiences. A composite description was then woven to provide a synthesis of meanings, and essences of the experience of living with an autistic child. Of course, their names have been changed to protect their privacy.

Clearing the Mind

Given my involvement with autism, the Epoche (Appendix A) process was extremely difficult. Clearing the mind of everyday clutter to accept the upcoming interview/experience as a new experience required me to set aside my life. As mentioned in Chapter III, I placed myself back in time to the simpler, carefree days of my life using classic rock, and recalling specific experiences of my youth on my way to interviews. During the interviews I was able to empathize with the participants, which gave me insight to their plight. The technique preserved needed empathy while enabling me to set aside preconceived notions. I did not anticipate answers to questions by the participants, or anticipate the behaviors of the autistic child. I did not predict family interaction, or the physical appearance of the house. The process allowed me to see the essences of the experience of living with an autistic child.

The Dual Interview Process

Having both parents present in the same room at the same time during the interview process proved invaluable in more than one aspect. Describing an experience from two perspectives gave depth to the responses. The two

perspectives were rarely the same; they experienced an event or day differently from their spouse. In most cases you could sense a newfound respect between the spouses for the difficulties each faced during their respective days. “I didn’t know that” was a common expression throughout the interview. It appeared that each did not want to burden the other with their daily lives. It also ensured accurate descriptions. The other refreshed more than once a spouse’s memory. It also provided useful observational notes for spousal interaction during the response.

After a question was asked, no order was followed concerning response. At times the mother responded first, at other times the father. Some shared in their answers, each interview was unique in the way the questions and answers unfolded. During the initial question: “Describe yesterday in complete detail,” close attention was paid to the different emotions experienced by the participants. The subsequent questions focused on these emotions. The dual interview process, in reality, provided 12 interviews not 6, and produced a rich, three-dimensional picture of family life with autism.

Family #1: Intense Love and Devotion

A Day

“When I wake up in the morning my very first thought is Jimmy, and I say a prayer and thank God for his progress, every morning is the same,” that is how Jack, Jimmy’s father, starts every day. Jill, Jimmy’s mother, starts her day by reading Jimmy his favorite book, 12 times, then fixing him French toast. Jimmy has French toast every morning; his diet is very limited. Further complicating his

diet is the fact that Jimmy cannot tell his mother what he wants to eat. “It’s a guessing game to see what food he will eat,” Jill explains, “he refuses to eat anything else but French toast, chips, and French fries; once in a while he will eat a hamburger.” Jimmy was diagnosed as autistic at age 2 ½; he is now almost 4 years old. Jimmy has made considerable progress in the last year, going from non-verbal to using picture cards to using small bits of communication. Jack, age 34, and Jill age 32, have put off having another child for fear of genetics being the cause of Jimmy’s autism.

The family lives in a middle-class development of new, well-kept homes in Northern Virginia. Their house’s interior is well kept and organized in a fashion that suits Jimmy’s needs. The walls in the living room are stacked full with interactive games and toys. Jimmy demands constant attention and during the interview Mom and Dad took turns engaging Jimmy with the games. Jimmy’s hyperactive chatter fills the room with constant noise; it is hard to concentrate. After a few minutes, I realize Jimmy is not communicating he is merely repeating every word said in the room. The repeating speech pattern is called echolalia, a common characteristic of autism. Jimmy’s constant echolalia is not communication, but the correct pronunciation of words is a good sign Jimmy does not suffer from apraxia, which is a speech disorder common in autistic children. Jimmy, and his parents are neatly dressed, and Jimmy has a recent haircut. “Jimmy doesn’t like haircuts, it takes both of us to manage him when we take him,” explains Jack. Jimmy is a beautiful child; autism has no physical defects (Sauna, 1986).

After breakfast Jack prepares to leave for work. “He is starting to understand the routine; six months ago he got very upset seeing me leave,” Jack explains, “I used to have to sneak out the door, now I think he is starting to realize I’m coming back.” Jack is constantly looking for signs that Jimmy “knows what is going on.” “Yesterday,” exclaimed Jack, “he was having breakfast and I was leaving for work, he looked up from the table said: “Daddy, have a nice day,” This made me feel like a million bucks!” The words, looked-up, are a very important part of that statement. Most autistic children will not make direct eye contact, even when they are engaged in an activity or conversation with another person (Coleman, 1989).

Jack has a stressful job managing 15 underwriters for a major insurance company. The job requires travel and is very demanding on Jack’s energy and time. He wrestles with the feelings of balancing job and family. As he gets into his car the thought running through his head is “how to get my work done and get home to spend time with Jimmy.” Jack confesses, “I need to get home, I have always felt this special connection between myself and Jimmy, even though he is not verbal.”

Jill, a homemaker, gives Jimmy her undivided attention after Jack leaves for work. They play games, and put together puzzles, and then run errands before his daily motor skills class at 11 A.M. Yesterday they went to the grocery store where Jimmy counted every aisle, laughing, and having a good time. “Before months of therapy this trip was not possible without Jimmy kicking, and screaming,” explains Jill. “Jimmy was frightened of new things, new people, and

new surroundings; we still follow a routine but things, people, and surroundings change.” Jack and Jill took pictures of places, people, and things with which Jimmy was familiar. They now use these pictures to show Jimmy where we are going and who we might see. This method lessens Jimmy’s anxiety. Jack states proudly, “This morning we showed him a picture of the bagel shop and a picture of you; he seemed fine with that.” While at the grocery store Jimmy ran into another cart pushed by a lady and her little boy. Jimmy did not respond when the lady and boy said hello. Jill explained that Jimmy didn’t talk a lot yet, and the lady replied that her son didn’t start talking till he was three. “I couldn’t get into another 30 minute explanation, and said goodbye,” Jill declared. After dropping Jimmy off at motor skills class Jill has an hour to do “what I want.” Yesterday she went to Wal-Mart to get a few things for the special gym set they are building downstairs to help with Jimmy’s motor skills. Most autistic children have poor coordination, and muscle tone. After class they go home, and have lunch then get ready for behavioral therapy, an intensive one-on-one daily 3-hour session supplied by a trained behavioral therapist from the Autism Learning Center. Jimmy has therapy from 1 to 4 P.M., Monday through Friday. According to the therapist Jimmy has had one of his best days for compliance, and paying attention. After therapy, Jill and Jimmy head downstairs to play games for an hour, or so, then return upstairs for more games and wait for Jack to come home. “Jimmy needs to be occupied and supervised at all times,” Jill explains. Yesterday, Jack called and said he was running late but would pick up Mexican

food on his way home. "I was happy to hear that," Jill said. Jimmy is a picky eater, and Jill knows he eats Mexican chips.

Yesterday's supper was different because Jimmy loves chips; it is one of the few things he will eat. Usually Jill must prepare two different meals, one for herself and Jack, and one for Jimmy. Dinner was also different explains Jill, "Because Jimmy actually sat with us the entire time." "Bedtime is surprisingly easy," Jack reports, "we have heard stories from other parents of autistic kids." "The music box is turned on and I cuddle with Jimmy until he falls asleep," Jill says, with tears welling up in her eyes. After Jimmy is asleep Jack and Jill have a few quiet hours to spend together before they retire to their bedroom. "I lay in bed and try not to think about the future," Jack says in a shaky voice.

Emotions

During our interview Jack and Jill were asked to describe experiences involving Jimmy that evoked joy, sorrow, anger, or any other heartfelt emotions. These experiences described by Jack and Jill produced tears, laughter, and sense of intense love and devotion for their child.

Jill began with a recollection of "a perfectly joyous day." Her parents had recently visited and stayed in a hotel with an indoor pool. "Jimmy is very timid around water, even bathtubs," explains Jill. "Jimmy surprised us all by jumping in the water, splashing around, and having a great time. That evening we all went out for dinner; Jimmy was exhausted. After dinner he spoke his first word; home!" Jack instantly started with his joyful memory. Jill's Grandfather had passed away, and Jack spent three days alone with Jimmy. He engaged Jimmy in

a color card game. Not expecting an answer, Jack pointed to a green card and asked Jimmy: "What color is this?" Jimmy replied: "Green." Thinking this was chance he tried a yellow card, and Jimmy replied: "Yellow." "I had never been so excited in all my life," exclaimed Jack! "I called my father, who is not an emotional man, and told him what had just happened. We cried for a long time not saying a word. This experience lifted me out of a hopeless rut I had been in for a long time." Jack went on, "Every cloud has a silver lining, and I think I would have missed out on a lot of things, I would have taken a lot of things for granted."

Sorrow enveloped the room as Jill began describing a devastating Christmas 1999 experience. This was the first time a lot of people were gathered at Jack and Jill's house. There was lots of confusion, people running around, laughing and having a great time. "Jimmy got confused, all he wanted to do was go to the basement," explains Jill. "Jimmy and I spent Christmas Eve alone in the basement." With a blank, tear filled stare she said, "I felt sad for Jimmy, myself, and our entire visiting family." The next day they went to Jack's sister's house for Christmas dinner. Jimmy was tired and before dinner his parents put him down for a nap. When Jill woke him for dinner Jimmy was disoriented. Jill states, "He didn't know where he was, he began hitting himself and me in the face. He did not recognize me, I couldn't settle him down. We just left, no explanations, no excuses, we just left." The next day they called Jack's sister to apologize for ruining the family Christmas dinner. Jill, surprisingly upbeat, remarks, "This

isn't the way life was supposed to be, we planned our lives together, we had a route; the diagnosis made us miss our exit, now we have to find a new way."

Jack began describing a permanent sorrow that he carries with him and is never "far from the surface." He tries to continue but is overcome with emotion and tears trickle down his cheek. He remembers vividly that while driving home after the diagnosis, thoughts about the future began rushing in from every corner of his mind. "As time went by the thoughts became overwhelming, it felt like I was in mourning, my dreams and hopes for Jimmy and for myself died on the day he was diagnosed." Jack begins expressing thoughts of deep sorrow, "My dreams were that Jimmy would go to college, get a great job, find the right person, have kids, and I would be a grandparent. Those normal hopes were turned upside down, I've had to adjust my hopes and dreams and look at things on a day-to-day basis." The reality is that Jimmy will probably not go to college, marry, or have children. The future is unclear for families with autistic children. Unlike children who are mentally retarded, or who have Downs Syndrome, the true potential of these children cannot be known, adding to the ambiguity of autism. Jack finishes, "I don't know about college right now, my main concern is getting him into kindergarten. I want him with other kids, if he has to go with an aide that's fine; then the goal will be for him to go without one. One day at a time."

Jack and Jill also described several experiences that evoked anger. Jill starts by illuminating an experience involving a neighbor boy. A few months ago Jimmy was playing with the boy and the boy told him he was really weird. "I

wasn't angry at the boy. He didn't know, I was angry at autism, and the situation knowing he would face these situations constantly." Jill continues, "Does he even know he is being made fun of?"

Jack continues with an incidence involving the school Jimmy attends, and their pediatrician. Jimmy's school insisted he have the chicken pox vaccine or a waiver from the doctor. Knowing there may be complications between autism and vaccinations, Jack, and Jill asked their pediatrician to sign a waiver form. The doctor would not sign, and began arguing with them about the necessity of the vaccine. They referred to the studies that might implicate the vaccine, but the doctor would not yield. "He was willing to take the chance of further damaging my son so he would not catch the chicken pox," Jack said with anger in his voice. Jack, and Jill were furious, and picked up Jimmy's files from the doctor to begin the search for a pediatrician who would sign the waiver. Eventually, they found one that did.

"We haven't heard from them since."

The topic turned to social outings. Jack begins to talk about a dinner with friends they see only about twice a year, and never before has dinner included their children and Jimmy. They were all invited out to dinner. Jack states, "the apprehension about what Jimmy might do caused a lot of anxiety; they know his diagnosis, but they really are not familiar with the characteristics." They were extremely nervous, "we took extra puzzles, toys, crayons, anything we could think of to keep him busy," Jill explains. Jack elucidates, "Other than a few minor

incidents he was fine, at least we thought they were minor, however, we haven't heard from them since."

Jack and Jill do not go out together without Jimmy. "No one understands his needs or routine, except maybe his grandmother," surmises Jack. Jill's parents have talked about moving closer, however, Jill says she discourages the move. While she admits it would be nice to go out once in a while, she says "the trade-off of having her mother there to help with Jimmy would result in another demand on the family's time. Jimmy demands constant attention, his schedule keeps us very busy, the routine will not let us have day-to-day extended family relations."

Structural Implications

Although only several experiences have been relayed, we must remember this family, and all the families interviewed live with autism everyday. Jimmy is an only child and this may be a contributing factor to the main issues with Jack, Jill, and Jimmy. Jimmy and autism have become Jack and Jill's all consuming focus. They allow no time for themselves, and do not allow anyone else into their lives. They rarely go on social outings, and would rather stay at home than feel the anxiety of unpredictable, embarrassing, behavior. In effect, they have put themselves inside the protective bubble of social isolation. The routine and intensity of living with an autistic child has taken over their daily lives, and allows no flexibility.

The intense, repetitive nature of Jimmy's behaviors, while disturbing my concentration, did little in disturbing Jack or Jill. While they are aware of the

abnormal behaviors, they have become accustomed to them. In the process of habituation (Hart, 1989), or becoming accustomed to their behaviors, the abnormal become the normal, which makes them easier to overlook.

Jack and Jill do not plan to have other children. Genetics has been linked as a cause of autism, passed on by one or both of the parents. By allowing autism to control the number of children they may want, Jack and Jill may begin to mourn for the family they never had, in other words, the “what ifs.”

Jack and Jill also suffer from ambiguous loss (Boss, 1999). Jack and Jill often refer to common milestones a normally developing child might reach such as high school, college, marriage, and children. After each was mentioned Jack and Jill would remorsefully offer alternative goals as a comparison. This has also been referred to as chronic sorrow (Burke, Eakes, Hainsworth, & Lindgren 1992). The parents mourn for their child everyday asking themselves questions that have no answers. This stressor remains unclear, indeterminate, and lifelong. As developmental milestones are not reached as anticipated the severity of the mourning increases. The ambiguity complicates the mourning process; it feels like a loss, but it is not really a loss.

Coping

All parents have expectations for their children, and so does this family. Jack and Jill have learned to use coping mechanisms in their family battle against the destruction caused by autism. The first I will call *expectation adjustment*. Jack spoke of learning to adjust his hopes and dreams, college plans, kindergarten, and just being with other kids. Jill spoke of finding a new exit for their route in

life. Important to notice is that they never mentioned these adjustments as lowering their expectations. These are their expectations for Jimmy. Second, Jack and Jill found extreme pleasure in the “*little things*” that Jimmy did or said such as matching a yellow card with the verbalization of yellow, or jumping into a pool. The “*little things*” are obviously connected to expectation adjustment. Third, they are learning to *adjust their lives from thinking distant-future thoughts*, which bring pain and sorrow because the future thoughts of parents with autistic children tend to be dismal (Sanders & Morgan, 1997), *to near-future thoughts and obtainable goals*. Fourth, Jack and Jill are concerned about the *well being of Jimmy beyond the years when they can take care of him or are deceased*. Despite the huge financial burden for Jimmy’s current care, they are setting aside funding for Jimmy in his adult years.

A necessary coping strategy for any successful marriage, especially one involving an autistic child, is *spousal support*. My observation was that Jack and Jill are in this for the long haul and fully support each other. Jack has taken a huge step in understanding his own frustrations and anger by seeking and obtaining therapy.

Although this family suffers from many of the stressors brought on by autism in the family, they also employ many of the coping strategies necessary to prevent or lessen the impact of the family crisis. Another factor is that the family is *able to derive positive meaning from the experience*, on many occasions stating that they feel they would have missed something, or would not have been able to appreciate the simpler things in life.

Family #1, although they are experiencing sorrow and anxiety, seem generally content with their role as parents of an autistic child. They love their child, and are exploring every avenue in their effort to help him. Jimmy, being their only child, causes all of their time and love to be extremely focused. They have no other children that need attention and love. The intense focus is on Jimmy. McHale (1986) suggests that families, which have more than one child, often adjust better to life with autism because they must try to maintain focus on more than one child's needs. Time will be the measure for Jack and Jill.

Family #2: The Frustrated Family

A Day

Bart woke up at 6 A.M. on Saturday. His mother, Betty, was then in turn aroused from her sleep. "We have been having trouble for about a year having him sleep by himself. I've been sleeping with him in the same bed," said Betty. When Bart, who is 5 years old, wakes up, the whole house is forced out of slumber. "He immediately begins to babble loudly, and run around incessantly," explains Bill, Bart's father. Barbara, age 7, tries to sleep in, but cannot, and shuffles downstairs for breakfast. "We had breakfast in shifts, Bart won't sit still, and somebody needs to watch him all the time," declares Bill. After breakfast the kids got dressed. "Barbara does fine, but Bart cannot dress himself, and he fights you all the way," Betty says in a tired, monotone voice. Bill adds, "After that we did the Starbucks run, and got Barbara a muffin to appease her." Parents often overcompensate in an attempt to make up for the constant attention that must be given to the autistic child (Mates, 1990).

Bart was diagnosed as autistic at age 2; he is now 5 years old. While making some progress cognitively, Bart has continual behavioral problems that have multiplied in the past several years. Bill, age 47, and Betty, age 37, are frustrated with their “intense lifestyle,” and look towards the future with anxiety. They also share concern on the effects that autism may have on Bart’s 7-year-old sibling, Barbara.

The family lives in a well-kept middle class neighborhood in Northern Virginia. The house’s interior is neat and clean. The walls are off-white, with few hangings, and furniture is sparse. The dining room, which is void of furniture, has games and toys scattered about. The pet cat wanders aimlessly through the house, often stopping at one of the exits to be let out. Bart is babbling and running around with an obvious accident in his pants. “We just can’t get him potty trained,” says Mom as she runs to catch and change Bart. Both parents look tired, but Betty looks exhausted. “It’s been a long week and weekend,” exclaims Betty, a financial analyst. “Weekdays are a little easier, when the nanny is here during the day.” Bill, also a financial analyst, agrees. Barbara is seen only once during my visit when she is forced to come into the room and say hello. “She is very shy,” explains Betty.

After breakfast Betty and Barbara head off to the consignment store; Betty is trying to get rid of the ever-growing mounds of clothes, and toys no longer used by the children. Bill and Bart go to a school uniform store. “We split up and take Bart to the easier places where he will not be a problem. I couldn’t imagine Bart in a consignment store,” explains Betty. She continues, “We always think

before we go anywhere about where we can take Bart and where we cannot; it's divide and conquer." After arriving at the uniform store, Bart refuses to leave the car. "He is very frightened of strange places," Bill elucidates. Bill quickly goes to the store and picks up a uniform, leaving Bart unattended for a few minutes. "You have to get things done," Bill admits.

After the uniform store, Bill and Bart went to a local playground. On the way to the park Bill remembers telling Bart that it was a great day. The sun was shining and the temperature mild for a winter's day. After arriving at the park Bart was running around not really noticing the other children. "The big thing today at the park for Bart was running around and saying, in a very loud voice, it's a great day, it's a great day," reports Bill. "He did not stop saying it for the 45 minutes we were there!" The other children were young and did not realize Bart was autistic. Bill comments, "I talked to one of the moms, but I could not tell if she noticed anything different." After the young children left a man stopped by with his two sons, they were a bit older. Bart continued to run around screaming, "it's a great day, it's a great day!" "They didn't stay very long, I think they were uncomfortable," Bill says, with a sad expression on his face. Bill goes on, "I am always conscious, particularly when he is with kids his own age, how striking the differences are. I study to see how Bart is communicating and socially interacting with the other kids, and how the other kids interact with each other." Bill struggles on in a shaky voice, "Bart is a nice kid; it really makes me sad."

After the park, Bill takes Bart to the mall for the "dreaded haircut." They passed by a huge play pit with hundreds of kids running around like pinballs in

a pinball machine. "Bart fit right in," exclaims Bill. Bill drags Bart from the pit and into Kool Klips. "They seem to have a handle on kids with special needs," says Bill. Before they found Kool Klips they would try different hair cutteries, always with the same result. "The haircutter would always start with this questioning routine, how long, what style, shampoo? They would see he is having a fit in my lap!" Bill continues with a scowl on his face, "I tell them: by the time you get done with the questions the haircut could be done; just cut the dam hair, but don't use the electric clippers, he will really lose it!" Following the haircut Bill must make sure all hair clippings are removed from Bart. "A total meltdown occurs if he finds one loose hair on him or his clothes," Bill explains. Upon arriving home Bart watches a video. "The videos seem to calm him down," explains Bill. Upon completion of the video Bart receives a bath just to make sure all the hair clippings are gone. "He really gets upset about the bath, especially washing his hair," Bill reports.

After getting through the rigors of the bath, it was lunchtime. "We never eat together," says Betty. In addition to eating in shifts, all of Bart's meals must be made separately; his diet is very limited. Also, Bart will not feed himself. "He would starve before he fed himself," declares Betty. Just as with hair clippings, Bart is very particular that nothing is spilled or dropped on him during his meal, or he will have a "total meltdown."

After lunch Bart is readied for therapy. "We give him something like benedryl to slow him down. The doctor said it was OK," Bill reports. In addition to 30 hours of therapy during the week he also has therapy from 1 P.M. to 4 P.M.

on Saturday. Betty and Barbara hit the neighborhood selling Girl Scout cookies, while Bill stretches out on the sofa in the room adjacent to the room where therapy is being conducted. Bill was able to hear a little of the interaction between Bart and the therapist. The first half hour Bart resisted, then peace was made. "Then they went outside, and I caught a nap," Bill says with a smile. Generally, Betty tries to keep Barbara out of the house on Saturday afternoon; she has been interfering with therapy. "Betty has been very good about taking her to a movie or shopping," Bill reveals.

Following therapy Bart watched a few more videos, and fell asleep around 5:30 P.M. He woke up around 7 P.M. and found a piece of hair, so Bill stuck him in the tub again. Everyone was fed by 8 P.M. Barbara picked out a Mary Poppins video to watch with Bart, but he really wasn't interested, and ran in and out of the room babbling. As he runs in front of the TV Barbara yells, "sit down," Bart sits for a few seconds and then continues his never-ending running and babbling. Bart and Barbara don't interact much. At times they may sing together, but other than that Barbara tries not to antagonize him; there is no physical contact. Betty describes their times together as "parallel play." "They may be in the same room, but they don't interact, and they play with different toys," she explains. "By 9 P.M. I was really exhausted," Betty says with a sigh. Bill retires to bed, followed by Barbara. Finally, Betty coaxes Bart to go to bed with her. At 3 A.M. Bart got up and started to babble loudly. "I guess that he eventually went back to sleep, I don't know, I was too tired to get up. Sometimes it gets to the point when your body will not do what you want it to," utters Betty.

Bart was downstairs running around at 6 A.M. when all were awakened by the noise. The next day starts.

Emotions

As with all of the families, Bill and Betty were asked to describe experiences involving their autistic child that evoked strong emotions. The experiences described by Bill and Betty produce a visible level of anxiety interspersed with moments of joy and sadness.

Bill begins with a story about the Little Engine That Could story. "I get a lot of enjoyment singing songs with Bart," Bill says. Several evenings ago Bart was in the bathtub and he and Bill were singing the Little Engine That Could song. "It is such a thrill hearing him know all the words and carrying all the notes properly, I just get real enjoyment from that," exclaims Bill. Betty can't think of any one instance, but she does derive a lot of joy out of reading the therapist's notebook describing Bart's day at home and at school. "Its nice to read about how Bart reacts with the other kids, if he did nice things on the playground, and so on," says Betty. She further states, "I like to think of Bart before therapy, and see how far he has come by watching him and reading about his day."

As our conversation moves on Betty talks about a sorrowful experience. Several evenings ago she was reading over options for saving for Barbara's college education. She started thinking of Bart, "Will he go to college? I hate to say it but should we even bother saving for Bart to go? Thinking about the future is very depressing." Bill agrees, "That's exactly what comes to my mind, the

future.” When he thinks of Bart being 15 or 16 he worries, “Right now Bart is loved by his family, therapists, and teachers. Last Halloween I was out with Bart and some older kids made some smart ass remarks about him. I started thinking about when he is in middle school and not surrounded by the people who love him. Will he be able to take care of himself?”

Next the topic turned to anger. Betty became very agitated and stated, “I’m extremely angry at the school system. I think there is a special place reserved for the people running the autism program there. I think it’s educational malpractice.” Betty claims the programs used in the autism program are 30 to 40 years old and that the programs have no data to suggest that they work. “They don’t work,” Betty declares. “I resent the fact that we have to pay \$40,000 dollars a year for an Applied Behavioral Analysis program the school system should provide. We pay for both private schooling and the ABA,” Betty reveals.

Bill finds people’s reactions frustrating when he and Bart are in a department store or a Starbucks waiting in line and it is taking longer than it should. “Bart starts running around, or rolling on the floor, and you get these looks from people,” says Bill. “You just want to tell them to stick it,” he exclaims, “and tell them if you had to deal with what a lot of us had to deal with you would be a little more tolerant of these types of situations.”

Betty starts as the topic shifts to embarrassing experiences. Again Betty doesn’t recall specific experiences, but rather, she generalizes, “At the grocery store Bart has frequent meltdowns.” Betty is at the grocery store often with Bart.

He finds it necessary to open every box or bag Betty puts into the cart. “Of course I can’t let him so he freaks out,” Betty explains. Bart screams and Betty knows the whole store can hear him, so she takes a deep breath and figures the quickest way to get through the store and get what she needs. “Because I am so embarrassed I rush and forget things, I know I’m in that grocery store 3 times a week,” Betty says with a look of frustration. Betty further explains, “I get weird looks from everyone, I’m sure they think he is just a brat screaming and yelling.”

As the interview proceeds Bill and Betty begin to disclose long buried thoughts not easily shared with family and friends. “Generally,” divulges Bill, “it’s (life with an autistic child) a cumulative, long path from the time your child is diagnosed by the pediatrician, to the endless school evaluations, through the school system, to finding the right process.” He continues, “It (autism) changes the whole dynamics of the family; socially, financially, and your hopes and dreams.” Betty begins talking about the “intensity” of everyday life, “We can’t do anything as a family, you don’t get a break, and I’ve had to curtail my professional life to take care of Bart’s needs.” Betty finds it difficult to watch as promotions are handed out to people who were hired after her. But she admits, “Even if I were offered a promotion I could not take it because of other priorities.” Betty continues to ponder her thoughts aloud, “It feels like you have a toddler around all the time, Barbara has grown out of that, Bart is still a toddler developmentally; it may never end. I wonder when my batteries will run out? Is he ever going to be easier to deal with? It’s pretty tough.”

Bill and Betty don't use respite care. "It (respite care) costs as much as therapy," explains Betty. Maybe, if we got away a couple of days a month I would not feel this way," Betty says with a tear in her eye. The couple's extended family lives out of state and visit seldom. "I love my family, but I really don't think they get it," explains Betty. She further states, "They try to sneak him cake and other things that Bart should not eat; it's hard when they come."

"It just isn't worth the hassle."

The conversation on social outings was rather short. Bill and Betty could only recall one family outing in the last year. They were invited to a friend's house for dinner just before Thanksgiving. Other families were also in attendance. Bill and Betty planned out a strategy before they went on who was going to look after Bart and for how long. They divided up duties so they could each spend some time talking to adults. "As soon as we got there Betty explained to the guests, that we didn't know, Bart was autistic, and might be a little disruptive. It was good that she did that right up front," explicates Bill. Bart spent the time walking around and babbling. "He doesn't do well in strange places," says Bill. "It (visit) went fairly well, but as you can tell we don't go out much as a family; it just isn't worth the hassle," explains Betty.

Structural Implications

Bill, Betty, Barbara, and Bart are a tired and frustrated family. The intense life they lead has taken control of their existence. Everything is focused, not on Bart, but the problems caused by Bart's autism. They are in need of family-based intervention (Bouma & Schweitzer, 1990) to hopefully prevent autism from

draining all the joy from their lives. Intervention programs for the families of autistic children not only should help to deal with the despair, shame, and social isolation, but also could help subside the obvious feelings of resentment the parents feel for their autistic child (Norton & Drew, 1994). The intensity of Bart's needs drives this family. As the interview and observations progressed the pain and frustration felt by Bill and Betty was obvious.

Bart has erratic sleep patterns (Norton & Drew, 1994), but the parents are the ones who are affected by the erratic sleep. Lack of sleep, as described by Betty, can have a relentless drain on family members' physical and emotional resources. Erratic sleep patterns are disruptive to the family routine and can result in less than normal functioning at work and at home (Hardman, Drew, Egan, & Wolf, 1993).

Bart's limited diet and inability to feed himself is also very disruptive to normal family routine (American Psychiatric Association, 1994). Bart suffers from many of the core set of impairments listed in the DSM IV in Chapter II. Among them are (a) inflexible adherence to specific, non-functioning routines or rituals, (b) failure to develop peer relationships appropriate to developmental level (does not interact with other children), (c) repetitive use of language, or idiosyncratic language (it's a great day, it's a great day), (d) repetitive motor mannerisms (incessantly running around), (e) hyperactivity, (f) short attention span (Mary Poppins video), (g) lack of language comprehension, (h) temper tantrums, and (i) giggling or weeping for no apparent reason.

Bill constantly compares Bart to normally developing children; this can be very harmful (Boss, 1999). They must learn to accept Bart for the child he is, not for what he was supposed to be. Both Betty and Bill share a pessimistic view of the future. They dwell on all the future milestones Bart will not achieve, such as college, and independence. They also worry about finances, and their own future survival dealing with the long-term burden of parenting an autistic child (Sanders & Morgan, 1997).

Barbara, Bart's sister, was very shy, and never smiled. She had to be forced to say hello to me. I am not assuming she suffers from depression, however, Gold (1993) reports that siblings of autistic children scored significantly higher on depression than a comparison group of normally developing children with normally developing siblings. Also, children with a sibling with autism tended to be more embarrassed in the presence of others (Roeyers & Mycke, 1995), probably because of the bizarre behaviors.

Social isolation (Gray, 1993) is the result of Bart's bizarre behaviors. Rather than go out as a family and function in society they have given in to the easiest, but most harmful path, social isolation. As Betty says, "It (going out) just isn't worth the hassle." Bill and Betty also isolate themselves from extended family which, when properly educated, can alleviate family stress through respite care and understanding (Dunlap & Fox, 1999). Bill and Betty don't use respite care. Relief from the constant demands of a child with autism is essential to the physical and emotional well being of parents (Norton & Drew, 1994).

Coping

As with family #1, Bill and Betty struggle with learning new coping mechanisms. Despite the many problems that plague this family, however, there are some glimmers of proper coping skills. They are financially planning for the future. They are not only planning for their later years with Bart, but also planning for Bart after their deaths. This, in the opinion of Norton and Drew (1994), is great source of stress relief. Betty and Bill are members of the local Autism Society of America Chapter. Betty has become an advocate for the rights of people with autism. Spousal support is evident in the splitting up of chores concerning Bart between Betty and Bill, and they are desperately trying to adjust their expectations for Bart. Though somewhat awkward in describing a joyous experience involving Bart, it was evident that they do derive joy from the “little things” done by or with Bart, i.e. singing a song with Bart in the bathtub.

Family #3: “Where has the Time Gone?”

A Day

Mitch and Mary got up at 7 A.M., an hour before their 2 children, Martha and Mike. Mitch got his coffee, and began searching the cluttered house for an invitation to today’s inaugural parade. He never finds the invite, and has a friend fax one to him so he can clear security. Mary begins taking down Christmas ornaments, a month after Christmas. The whole family was to attend the parade, which was being viewed from the office building where Mitch works as a lawyer. “We were all going to go,” exclaims Mitch, “but, the night before, I was informed that Martha had a birthday party to go to, and Mike had a doctor’s

appointment, so I was going alone.” Mitch gets dressed and is on his way to the parade. Today’s activities will be taken care of by mom. Mike, the couple’s 7 year-old autistic son, and Martha, the couple’s 8 year-old daughter make their way downstairs. They watch the Disney Channel for a while and then have breakfast.

Mitch, a 44 year old lawyer and his wife Mary, a 45 year old lawyer, express frustration on the inability “to get things done,” and consider the lack of opportunities to do things as a family very stressful. “This (the parade) is just another case of the frustration and stress I feel of not being able to spend a whole day with my kids at a great function like the inaugural parade,” explains Mitch. The family has tried to move some of Martha’s activities, which include ballet, and gymnastics, to times during the week to free up some family time. “But those time periods always get filled up by choir or whatever; it’s a constant source of frustration,” laments Mitch.

Both parents work long hours. A typical day is 11 hours. Mitch and Mary try to spend time reading, and playing games with the kids in the evening. “My daughter finds the computer and her friends more fascinating than me. I’m feeling like my daughter is growing up, and I’m not having the interaction with her I want to have. It seems I have no control over the time I want us to spend as a family; it’s very upsetting for me,” bemoans Mitch. He continues, “Self-inflicted guilt and selfishness is terrible; it’s frustrating.”

Adding to the frustration is the fact that Mike and Martha have different activities that they are capable of doing. “Mike can’t do the things that Martha

can,” says Mitch. Martha ice-skates, loves to ski, and enjoys gymnastics. Mike cannot master those skills. Mitch explains, “It seems we are always split up when we spend time with our kids. Seldom are we together as a family, that’s the frustrating part, it hurts.”

Mike was diagnosed with autism at age 3; he is now 7. Mike continues to make progress in behavioral and cognitive areas, but his autism is clearly noticeable. He is not social, does not verbally communicate, and has behavioral issues. His sister seems somewhat shy, but has a good social life. Martha attends therapy sessions to deal with her resentment of her brother. She often expresses anger toward him, and often wishes him dead.

The family lives in an upper middle class neighborhood in Northern Virginia. The house is spacious, as is the lot on which it sits. Although in a suburb of Washington, D.C., the setting seems very rural with streams, trails, and a wooded back yard. Inside the house is cluttered and unkempt. Dishes are piled up, and Christmas trees are present in 2 of the rooms. This struck me as strange considering it is January 21st. One large room has rows of shelves packed with games and toys. In the same room trains and train tracks cover the floor. The train whistles are heard throughout the interview. Mike has an obsessive fascination with trains, and was seen throughout the interview playing with them. The family employs a nanny during the day, but cleaning is not one of her duties.

After breakfast the dash begins; first the search for a birthday gift for Martha’s friend, then back home to meet Mike’s therapist. Mike has behavioral

therapy every Saturday. Today the therapist is taking him to a motor skills class and Mary is notified that today is parent's day. So off they go to Mike's class. We watched him, he did great," exclaims Mary. She proudly continues, "He is so funny, he slowly aimed the rolls toward me, it made me feel great!" After class Martha was dropped off at the birthday party, and Mike was taken to his doctor's appointment. Mary explains, "He is a holistic doctor, it sounds strange but we took him, what can it hurt." Mary goes on, "I kept thinking of faith healers and stuff, it struck me as comical. Then he started making sense talking about vitamins, cell structure, etc. What the heck, we'll try it, it's all natural." After the doctor, Martha was picked up and they spent some time at the library researching a suitable family dog. "Martha wants a dog, and I told her she has to research and find a dog that will survive in our family," Mary says with a chuckle. While at the library Mike starts shouting, "Pokemon, Pokemon." Mary finds a Pokemon book and Mike is happy for a while.

Everyone got home around 6 P.M., and had dinner. Mitch fixes the family computer, and Mike watches Martha play games for the rest of the evening. Mitch laments, "The computer consumed them both; I lost them for the evening." Mike fell asleep and Mitch carries him to bed. He will not stay in his room if he goes to bed before he is asleep. "He always gets up in the middle of the night, and you hear him stirring around," Mary says in a surprisingly calm voice. She continues, "The next thing you know he is in bed with us. This happens every night; it's not bad he is a cuddly kid."

Emotions

The topic turned to happy experiences involving their autistic child. Sue excitedly started the conversation with a Christmas story. This Christmas Mike wrote his own name on thank you notes, with very little guidance. Usually Mary has to draw dots so Mike can connect them. “I didn’t think he could do it. It was slow but he did it! Plain as day it was M-I-K-E,” roars Mary.

Mitch chimes in excitedly about a recent swimming adventure, “A year ago I took Mike swimming and he went crazy. He was screaming, and running around. He would not go near the water.” Recently Mitch took Mike swimming again. “I was very apprehensive, you never know how he is going to react,” explains Mitch. Mike saw Mitch packing his swim trunks and was not happy, but he got in the car. Upon arriving Mike was hesitant about putting his trunks on. Eventually they made their way to the pool. “He took to it like a fish to water, I was ecstatic,” exclaims Mitch, “He really can’t swim, but he paddled around with no apprehension.” The whole experience was joyful for Mitch. Mike didn’t get upset by anything or anyone, not even a trip to the bathroom. “Usually he drops to the ground, you know, dead weight,” explains Mitch. Mitch also talked about a recent trip to Disney World, “There were only 2 mishaps, the plane trip was stressful, and Mary was on standby while Mike, Martha and myself boarded. Mike didn’t think Mary was coming and had a complete meltdown.” Also, while at Disney World, Mitch took Mike on a ride he assumed he would enjoy, but it frightened him. “He shook for hours, I still feel guilty about that,” Mitch says in a hardly audible voice.

The conversation took on a more somber tone as sorrowful experiences were relayed. The family went to the beach last summer, and rented a house with some relatives. The house was 3 stories high, with balconies and sliding glass doors on all floors. Mitch installed bolt locks on the entire upper story sliding glass doors. On the third floor is a bedroom, used by Mitch and Mary, with a balcony that hangs over a cement driveway 3 stories below. Mitch was watching Mike for the afternoon and had put him in that bedroom while he made some phone calls. Suddenly Mitch's brother is shouting at him from outside, "Mike is out on the balcony hanging on the gutter!" Mitch forgot the bolt lock and Mike had climbed up on the balcony railing, grabbed the gutter and began inching away to the point where the balcony was no longer underneath him. Mike was having the time of his life, no fear, just laughter. "I ran out on the balcony and stopped in horror as I saw him inch further away," Mitch says. Trying not to startle him Mitch moved slowly towards him and managed to grab his shirt just as he was falling. Mitch bewails, "I'm still shaken to this very day. Through my own negligence I could have caused my son's death."

On another occasion Mitch, Mary, and Mike were in the back yard cleaning up leaves. "I looked up and didn't see Mike," says Mary. They searched and searched, yelling his name, but they could not find him. An hour passed; panic set in. Mike wasn't at the neighbors, or the creek. Mary called the police. Soon after they arrived and Mary was showing them a picture of her son, Mike comes wondering down the road. "We still don't know where he was, he can't

tell us. He has no sense of fear, you have to watch him every second; it's very intense. He doesn't answer when he is called, and he can't tell if you are upset," Mary explains in a very tense and emotional voice. "I feel responsible for these accidents," says Mitch, "so now I don't take my eye off of him. As a result I don't get much done around the house." He continues, "The leaves are still in the gutter from the fall, we both have to be here so one can watch Mike, while the other does chores."

Anger was discussed next using two past experiences that remained vividly in Mary's mind. The family decided that a skiing trip was in order. Mike had been skiing only once, it was not a pleasant experience. They went ahead with their plans. Mary tried to get Mike to the bunny trail and up the towrope. He fought, but she finally managed to get him up to the top of the gently sloping trail. He came down with total assistance from Mary; he did OK. Mary was determined to get him back up to try again. When she tried to get him back up the tow he threw a large fit. He was screaming, hitting Mary, and himself. He threw his hat and gloves off, and began rolling in the snow. "I had to pin him to the ground, it was the only way to control him and get his skis off," explains Mary. At that point a member of the ski patrol team approaches Mary screaming at her for abusing her child. Remarks such as, "Why are you sitting on that child?" and "What kind of mother are you?" were hurled at Mary. "I told him to mind his own business, and to shut up if he didn't know what he was talking about," Mary elucidates. She continues, "I'm usually pretty thick skinned about this kind of stuff, but he made me angry." Another time Mary and the nanny

were at a museum. Mike didn't want to leave a particular room, so he dropped to dead weight. They tried to get him up but he refused and began to scream and kick. A guard came over and asked them to step aside. He thought they were trying to kidnap him. The guard began asking Mike questions, "Is this your mommy, where do you live?" Of course Mike couldn't answer him. "I had to go into a 15-minute explanation of autism before he would let us go. I don't get embarrassed much anymore, I just get angry sometimes," explains Mary. "You can never tell what his reaction is going to be at any time to anything," Mitch explains. He continues, "We went to a restaurant in Disney World with all the life size characters walking around. Mike loves them on TV, but he was scared to death and freaked out."

"Mike is always left out."

The family's last visit with extended family was Christmas Day. They all went to Mitch's brother's house near Baltimore. His brother has two children the same age as Mitch's. Mary's sister, who lives nearby, was also there. She has three children. All the kids were getting along except for Mike. "Mike is always left out," explains Mary. "Mitch's sister is very fussy about her house; she keeps it neat and doesn't like the house messed up. Her kids are very self-centered, they won't let anyone else in their rooms," explains Mary. "Their son also likes trains; in fact he had a train that he had gotten for Christmas on the floor. It (train) was nothing special, just an electric train on a round track," says Mary sarcastically. She continues, "They wouldn't let Mike touch the train, they were really bent out of shape. They knew Mike was coming, they know he is a train-

aholic, why make me keep stopping him from playing with it?” Finally the train was put away. “Then Mike was really left out,” Mary said sadly. While the other kids played Nintendo, Mike was left by himself to wander around all day.

“That’s depressing. It’s always a problem no matter who we visit,” says Mary.

Mary and Mitch prefer to entertain friends and family at their house. Mary explains, “Our house is always messy, Mike can’t hurt anything here. He knows where everything is and he feels comfortable.” Mary laughs and continues, “Although he does like to throw his shoes in the fish tank and hang off the balcony.”

Structural Implications

Mitch, Mary, Martha, and Mike are a generally happy family. Mitch and Mary try to find humor in their situation and often do. They do not dwell on the future. In fact, the future does not seem to be of concern to them, not mentioning the future once during the interview. Mitch and Mary’s main sources of stress fall into two categories. *First, they find it very difficult “to get things done,”* because of the peculiar and relentless nature of Mike’s behaviors. Mary noted that they have to watch Mike every second, while talking about his disappearance from their back yard. Mike then strolled up the road unaware of his parent’s concern, and seemingly lost in his own world. Frith (1993) attributes this behavior to a major cognitive deficit, in which autistic individuals seem lost in their own world, and also limits their ability to imagine another individual’s state of mind. Mitch added that he couldn’t take his eyes off of him. He notes that this is the reason he gets very little done around the house. Coggins and Frederickson

(1988) talk about the relentless nature of autism, but provide no examples. A more suitable term in my opinion is the *intensity of constant care*. Norton and Drew (1994) briefly discuss the autistic child's tendency to be continually frightened of harmless things, while seeming oblivious to actual threats and dangers, another aspect of autism that requires constant supervision. This is perfectly illustrated when Mike hangs precariously from a third floor gutter having the time of his life, and on the other hand being terribly frightened of Disney characters.

Second, Mitch constantly remarks about the lack of opportunities to do things as a family. He feels he has lost control over the time the family can spend together. One contributing factor is Martha's schedule. Parents often over compensate in an attempt to make up for the constant attention that must be given to the autistic child (Mates, 1990). Another factor not allowing the family to spend time as a unit is the separation of the siblings due to different skill levels and interests. I have referred to this as divide and conquer.

As listed in the DSM IV (APA, 1994), Mike clearly displays a severe lack of social interaction, a lack of development of spoken language, an encompassing preoccupation with inanimate objects, i.e. trains, and has apparently inflexible adherence to non-functional routines or rituals, i.e. skiing incident and museum incident. Mike also displays temper tantrums, and some self-injurious behavior as displayed in the skiing incident. Another behavior exhibited by Mike is erratic sleep patterns, in which he constantly wakes up in the middle of the night, and gets into bed with his parents. The erratic sleep behaviors do not upset Mitch and

Mary at present, but I can assure them it will if the behavior is not stopped, and they find a 20-year old autistic man in bed with them every night. Mitch mentions on numerous occasions about Mike's unpredictable behavior, never knowing how he will react to a new or recurring experience. Haefle and Henggler (1983) report unpredictable behavior may make it difficult to take the autistic child out in public, thereby limiting family outings.

Mitch and Mary reported no social outings with friends, and limited outings with extended family. Gray (1993) reports that as a consequence of the behaviors of autism, many parents tend to isolate themselves from social contact with the outside world, and furthermore, the social life families do manage to maintain are restricted to their extended family, and a few friends who can deal with their child's condition.

Coping

Martha, Mike's sister expresses deep anger and resentment toward her brother. McHale, Sloan, and Simeonsson (1986) report that many siblings of autistic children feel they have not received the same amount of attention from their parents as the impaired child, and express feelings of unfair treatment, with their sibling able to get away with more than they ever could. Many also find the bizarre behaviors embarrassing when they are with their peers. Martha attends sibling therapy. The use of sibling groups has been effective in that these provide siblings with peers with whom they can talk about their brother or sister with autism (Gold, 1993). Mitch and Mary also set aside time specifically for activities

for Martha, another way parents can minimize the effects of autism on siblings (Howlin, 1988).

Mitch and Mary are involved in the local Autism Society of America chapter; Mitch was a past president of the chapter. Participation in support groups, such as the Autism Society of America, allows association with other parents of autistic children and fosters cooperative efforts directed toward development of needed family programs (Sanders & Morgan, 1997).

Humor and spousal support help alleviate the stress caused by autism (Konstantareas, Homatidis, and Plowright, 1992). Mary often mentioned how “funny” Mike can be, and Mitch told stories that made us all chuckle. Hand-in-hand with humor are the “little things.” For instance, Mary’s joy when Mike rolled toward her in gym class, and the sheer excitement and joy she experienced when her 7 year old autistic son wrote his name on thank you cards. Mitch could hardly find words to express his joy when Mike actually enjoyed swimming. The “little things” evoked joy and clearly displayed the family’s willingness to adjust their expectations. To accept their son for who he is and not what they think he should have been reduces the ambiguous loss (Boss, 1999) Mitch and Mary may feel.

Mitch and Mary continue to push Mike into new activities, and even continue trying activities that Mike has done poorly in the past, such as skiing and swimming. Their emphasis here appears to be on living as normal a life as possible. This process is known as normalization (Gray, 1993).

Family #4: The Angry Family

A Day

Amy and Archie are up at 5:30 A.M. every weekday morning getting ready for work. Before they leave notes on Andy's behaviors from the night before are written in a notebook they keep for Andy's therapists and teacher. Andy, the couple's autistic 7-year-old son, sleeps soundly most nights, and is up just before his parents leave. They struggle to get his attention so they can say goodbye, as Andy darts from room to room. They leave and the AuPair continues this routine of feeding and clothing Andy. The day is relatively uneventful at work for both parents. There are no frantic phone calls, which they both experience often, from teachers or therapists experiencing severe behavior problems with Andy. Archie has repeatedly heard from Andy's teacher about his abusive behavior. "I was once called when Andy was uncontrollable, and an aide tried to settle him down. She ended up with a broken ankle," Archie says in a depressed, monotone voice.

The family lives in a middle-class neighborhood of neatly arranged older homes. Inside the house is spotless and filled with antique furniture. There were no toys or games visible. Andy was obsessed with my tape recorder, and nearly made the interview impossible. Luckily I found the spare recorder I keep in my bag, and let him play with it. During the time I spent with the family Andy was uncontrollable, shouting and screaming loudly when all attention was not focused on him. The behavior was so intense it was distracting to all, especially to Amy, who could hardly control her anger. Andy was very physical, and even

when displaying affection managed to knock the eyeglasses off his parents. Interactions with Andy came in the form of constant attempts of distraction by the parents giving him picture albums to keep him busy.

Archie, a 48-year-old lawyer, and Amy, a 51-year-old director of human resource development, enjoy and are dedicated to their occupations. They usually get home around 7:30 P.M. “Upon arriving home,” explains Amy, “Andy wants our undivided attention.” The phone rings shortly after Amy gets home. “As soon as the phone rang he (Andy) started screaming,” declares Amy. Andy follows her from room to room screaming while she attempts to talk to a fellow employee about a problem at work. “I could barely get through the call, it’s so frustrating when I can’t communicate and get things done. I get very angry and frustrated,” Amy says in an infuriated voice. She continues still angry, “Either he chased me around all evening or I chased him.” Archie adds, “I tried to distract Andy while Amy was on the phone, but it didn’t work. He just prefers his mom.”

Eventually Andy is prepared for bed. His pajamas are put on and his teeth brushed. “We try to read to Andy every night,” says Amy. After a short story Andy pushes his mother out the door. “When he is ready to sleep he literally pushes us out the door,” explains Amy. Tomorrow is Saturday; they will spend the whole day with Andy.

Emotions

As the topic turned to joyous experiences involving Andy, he continued his relentless screaming. Amy recalled a night the previous week, however, when she came home a little early. "I came home a little early, around 6 P.M., and surprised Andy and the AuPair. Andy was surprised to see me. He ran to me and threw his arms around me, kissed me, and hugged me," exclaimed Amy. She adds, "That was joyous." After pausing for several minutes, Amy says, "Another time we took him ice-skating and he really took to it. It made me happy to see him enjoy something."

On a somber note Amy speaks of sorrowful experiences. "Anytime I take him to a birthday party I'm sad," she says in a shaky voice. Amy continues after regaining her composure, "I see how different he is from his peers, the contrast is so vast, it really makes me sad." Archie is saddened by the rejection of Andy by the kids in the neighborhood. "They won't play with Andy; they say he is creepy, that hurts," laments Archie.

When the topic turns to experiences involving anger Amy enthusiastically says, "I've got plenty of those." She focuses on times when Archie is away on business; he travels a lot. Andy becomes even more unruly, not listening, and his behaviors become more relentless. "Finally I have to hold his little head to make sure he is hearing me, and I tell him to stop the craziness, and he laughs hysterically." Amy proclaims, "Its hard to have a demanding job and a demanding child such as Andy. When I come home I'm tired." Amy begins to sob tears of anger. After a pause she continues, "When he (Andy) is in the out of

control mode, usually when Archie is out of town, it's almost unbearable."

"Sometimes I don't think I'm going to make it; I get so angry." Archie replies in a defensive tone, "I know I increase Amy's burden when I'm away, but what can I do? I get angry because I hear about it all the time, and frustrated because I can't change it." Archie is also angered by Andy's willful behavior. "The obsessive-compulsive behaviors really upset me," Archie explains. When in the car Andy always argues about the door locks being down in the car, and about going straight when Archie has to turn. "Fighting those battles really hacks you off sometimes," exclaims Archie.

Archie is embarrassed by the endless, bad school experiences. He recalls one experience when he volunteered to help in Andy's music class for a parent presentation. "Andy really started to act up, rolling on the floor and screaming," says Archie. The principal pulled Archie aside and asked if he would come to her office where she asked him to take Andy home; he complied. "He (Andy) was really screwing up the presentation, I understand," says Archie. He continues as he looks toward the floor, "I felt awful, but I did it."

"Andy has to go to the bathroom."

Amy, Archie, and Andy recently went out for dinner. They seldom venture out to a restaurant. "Every time we go to a restaurant it's an embarrassing situation," explains Amy. "As soon as we walk in the door Andy has to go to the bathroom. That's always the first step anywhere we go, kind of strange," explains Archie. After the ritual bathroom trip, Amy pins him in the booth. Andy begins talking loudly. The food is served as Andy wiggles his way

onto his mother's lap. "He has to sit on my lap when I'm eating," she complains, "and if somebody in the restaurant drops something on the floor he (Andy) runs to pick it up." Archie adds, "When we really want to do things, like have friends over, it's better to have him out of the house. He demands all of the attention."

Structural Implications

The intensive nature of Andy's behaviors has caused the degeneration of any semblance of family normalcy. Anger, frustration, and embarrassment have replaced normal family development. They hurry to work in the morning, leaving the Aupair with parental duties. They arrive home late and almost find the evening unbearable. Interactions with Andy are used to distract him, not engage him.

Andy is a physical child. He has hurt himself and others. Abusive behavior, according to Konstantareas (1989), turned out to be the best predictor of stress for parents. She also reported that parents of such children reported feeling helpless, overwhelmed, and frightened by their child's behavior. Furthermore, these parents frequently interpreted abusive behavior as a reflection of their child's inability to relate appropriately to them, their own poor parenting and management skills, and their general ineffectiveness in parenting them.

Besides abusive behavior Andy exhibits a host of other behavioral characteristics of autism listed in the DSM IV (APA, 1994). The failure to develop peer relationships appropriate to developmental level is demonstrated by Archie's summation of Andy not being able to play with kids in the

neighborhood, and sorrow Amy felt because of the vast developmental differences she sees between and his peers. Encompassing preoccupation with one or more stereotyped and restricted patterns of interests which are abnormal in either intensity and focus, as demonstrated by Andy's obsessive behavior with the recorder, the door locks, and going to the bathroom. Andy also suffers from hyperactivity, impulsivity, bizarre movements, short attention span, and tantrums involving either loud speech or screaming.

Andy's severe behaviors have isolated them from social contact with the outside world. Sanders and Morgan (1997) conclude that the strong feelings the parents of autistic children have about their child's negative characteristics place them at higher risk for withdrawing into the family and making less use of social supports and outside activities that may alleviate stress.

Amy and Archie direct their anger not at negative situations, or people ignorant about autism, but at Andy, and each other. There appears to be little spousal support, and a lot of resentment. They are taking no steps to get the help they need, such as family therapy.

Coping

Archie and Amy's main coping mechanism is that of avoidance. Leaving early for work, arriving home late, and frequent business trips provides escape from family life. They are trying to reduce Andy's behavioral problems with ABA, a form of behavior modification. Koegel and Koegel (1990) suggest that reducing the child's behavior problems holds the potential for reducing stress for the parents and the family as a whole. A study by Koegel, Schreibman, Britten,

Burke, and O'Neill (1982) reports that while parents with an autistic child were initially quite low on time spent in recreational and leisure activities, those parents who provided behavior reducing therapy reported significantly more time in recreational and leisure activities than did the parents who had not been provided with behavioral training for their child.

Although struggling with the concept of adjusted expectation, Amy did find some solace in a hug and a kiss from Andy upon her early arrival from work. The "little things" again provide joy to Amy. Another example is the joy she experienced just knowing Andy was enjoying an activity (ice-skating).

Family #5: "Always on our mind"

A Day

Lyn gets up around 6 A.M. every weekday morning. Today is no different. She pours herself a cup of coffee and attacks her e-mail. Lyn has adjusted her workload to be able to do most of it from home. She can spend more time with the girls that way. Laura, age 4, and Liz, age 5 stumble downstairs around 7A. M., and have a seat on the sofa to watch a few cartoons before breakfast. Larry rumbles downstairs, says good morning, and is off to work. "I don't have much involvement with the kids during the day," Larry confesses. Lyn gets off the computer and continues her day getting the kids fed and dressed. "Some mornings are better than others," says Lyn, "Breakfast is difficult, Liz is a very picky eater." After breakfast she hustles the girls upstairs to get dressed. Liz, the couple's autistic daughter, insists on wearing blue, and Lyn gives in again fearful of upsetting her. "It's really a struggle with Liz's hair,

and getting her shoes and socks on is almost impossible,” exclaims Lyn. Both girls get things ready for show and tell at school, with no prompting. “Last year, Liz would not remember show and tell, this year she wants to do it every day,” Lyn says in an excited voice. The girls put their show and tell items in a bag, and they are off to school. Both girls attend a half-day preschool. Lyn gets back home and continues her work as an account executive for a major computer company. “There is hardly a minute goes by that I’m not thinking of Liz and how she is doing,” says Lyn, “she is always on my mind.”

Larry, a 37-year-old engineer, and Lyn, age 41, live in a neat, middle class neighborhood in a spacious, new, well-kept house. Their 2 daughters, Liz and Laura are beautiful, blond haired children. The home is comfortable, and inviting. The children are present during the interview, and except for a few minor outbursts it is calm. The parents are constantly interacting with the children playing games, and “styling” their mother’s hair. The minor disturbances are from Liz fighting with Laura over toys. “You’ve got to correct her, but seeing the sibling rivalry is great,” Lyn says in an animated voice. Interaction with peers or siblings is not common in autistic children (APA, 1994). Liz seems a little distant, and eventually wanders into the next room and becomes fixated on the computer.

The babysitter picks the girls up from school, and the girls have lunch at her house at 12:30. A therapist comes to the babysitter’s house, and works with Liz from 1 P. M. to 4 P. M. while Laura takes a nap. At 5:30 P. M. Lyn picks up the kids, arrives home, and begins preparing dinner. “I prepare three different

dinners; one for Liz, one for Laura, and one for Larry and me,” says Lyn. After dinner, the kids play on the computer, and Larry watches some TV. At 8 P. M. their favorite TV show came on, Survivor, and they all piled on the sofa to watch. Liz sat on Lyn’s lap during a part of the show that the contestants eat bugs. “Liz thought that was terrible,” exclaimed Lyn, “She kept saying, are they going to eat those bugs?” “It was great to see her paying attention,” says Lyn. After the TV show, Lyn and Larry try to get the girls to bed. Laura gives up without a struggle, but Liz insists on staying downstairs. “I had to turn the lights out on her,” says Larry. After 45 minutes in the dark, Liz comes upstairs. “I usually cry when I put Liz to bed. She is such a sweetheart, my heart aches for her, I just want her to be OK,” Lyn says with tears welling in her eyes.

Waiting for Liz to make her way upstairs, Larry and Lyn discussed what next year would bring in terms of school placement for Liz; placement is a major concern for them. Liz relays the context of the conversation, “Before we got the diagnosis, you always wonder what your kids are going to be when they grow up, and where they will go to college. After the diagnosis we were more focused on the short term. I just want her to get into a normal kindergarten, with normal kids. I don’t know if that will happen, it’s up to the school system. Our thoughts have gone from thinking about the future to just thinking about tomorrow.”

Emotions

The topic turned to joyous experiences involving Liz. Larry recalled a situation involving his father. The family lived with Larry’s parents during the construction of their present home. Liz enjoyed the time with Larry’s father. “At

that time Lyn was traveling extensively for business, but grandpa was always there, and they grew close,” Larry explained. When the family moved into their new home Larry’s folks would come over and Liz would literally try to push them out the door. “I guess Liz thought that meant Lyn was going on another trip,” figures Larry. Just this past weekend Larry’s parents were visiting. “As they were leaving, Liz jumped up and grabbed my dad, and kept saying don’t go. That made me really happy, the timing could not have been better,” exclaims Larry. Larry’s father had just begun treatment for prostate cancer.

Lyn chimes in with a joyous experience involving both children. “I feel really joyful when I see Liz and Laura playing together. A year ago that would not have been possible,” says a happy Lyn. She continues, “Just to watch them play together, and have Liz actually initiate play is just incredible.” Lyn also speaks about a birthday party both girls were invited to this past weekend. Liz did well at the party playing with the other girls, and participating in the party games. “Just to see Liz fitting in with 15 other little girls was real joy. Liz didn’t miss a beat, she played the games, she really participated,” says an elated Lyn.

As the conversation turns to experiences involving sorrow, Larry begins, “It was a couple of months ago; Laura got invited to a birthday party, and Liz didn’t. When that Saturday came, and we told Liz she couldn’t go she was really upset. The part I really got sad about was when I started thinking about Liz’s future. How many times will she be left out?” Lyn recalls a family reunion that took place on a cruise ship several months ago. They had never been on a cruise, and were looking forward to spending time with their extended family on

a cruise ship. The second night they were aboard was formal night for the adults. The ship was equipped with a childcare center where the girls would spend the evening. “Within 5 minutes the pager went off,” explains Lyn. Liz had a meltdown, and had to be separated from the other children. The staff could not console Liz so Lyn went to pick her up. “The situation was so sad for me because I thought we had come so far,” Lyn explains. She continues tearfully, “It really drove home the fact that she was different from the other kids.” For the rest of the trip Liz would not allow herself to be separated from her parents. “Every time we would pass the room we took her to that night she would say, she (Mommy) lost us,” Lyn remembers. Lyn goes on, “After we got home one of the therapists asked her about the cruise, and she started to cry.”

“The first time I was really angry involving autism it was directed at a local major university for putting a label on my child after only a half-day observation,” declares Lyn. Lyn and Larry remember sitting in a room, and being handed the diagnosis of autism. “The psychologist told us he would change the label to PDD if would make us feel better,” Lyn heatedly explains. “Basically they just handed us this report and that was that; no support, nowhere to go, whom to call, or whom to see,” Lyn says still fuming. Caramagno (1992) reports that most medical doctors and psychologists know very little about autism and the treatment options available. “Delivering news like that is life-changing; they treated it like she had a cold,” says Lyn still furious. Larry recalls an experience with the school system during a school evaluation, in which a school psychologist wanted to label Liz as learning disabled. That was fine with Lyn

and Larry because they wanted the services associated with that label. Then the psychologist made an unfortunate statement. She said, "Let's go for that label now, it may turn out that she is just retarded." Larry felt the blood rush instantly to his head in anger, and asked, "What does just retarded mean; nobody is just retarded." Larry classifies that statement as, "The most insensitive thing I have ever heard."

Embarrassing experiences can be, with afterthought, slightly funny or painfully indelible. Lyn and Larry recall one of each. "There is a cashier at a grocery store we go to that wears a lot of makeup, I mean a lot," explains Lyn. As Liz and Lyn were checking out Liz looks at her and proclaims, "Halloween, Halloween, wow!" Lyn professes her extreme embarrassment as she chuckles. Larry took Liz on one last ride at Disneyland knowing that catching their flight home may be in jeopardy. "I had to let her ride the carousel one last time while Laura and Lyn finished packing the car to go to the airport," explains Larry. After the ride was over Larry explained to Liz it was time to go. She refused and fell to the ground kicking and screaming. "I had to carry her to the car while she kicked at me and screamed the whole way. I mean it was a real show, the whole way through the park," says Larry. He continues, "The people didn't know why I had to do that; they must think I abuse my kids."

Constant bathroom trips

Next, Larry and Lyn are asked to describe a social outing as a family and their last outing involving extended family. A trip to the local steakhouse was proclaimed as relatively uneventful, aside from the constant bathroom trips by

Liz, and her fascination with a crying baby. “Liz got up and tried to console the baby, but the mother looked a little nervous, and we sat Liz back down,” says Lyn. Christmas was spent with extended family, all of which are local. “She did very good this year, except for the eating part,” Lyn says proudly.

Larry concludes, “I think we feel pretty lucky. I think Liz is really doing well and she is not as restrictive as most other autistic children are. She (Liz) has really come a long way this past year; therapy has really changed her, and our outlook is positive.”

Structural Implications

Lyn, Larry, Laura, and Liz are a delightful family, and they are dedicated to keeping it that way unwilling to let autism control their life. They have been able to adjust their expectations, and turn those expectations into Liz’s milestones, thus minimizing ambiguous loss (Boss, 1999). For example, Lyn sees Liz as reaching a significant milestone when “Liz fits in with 15 other little girls.” This adjusted developmental milestone arrives years late for Liz, but to Lyn it is a huge milestone. The family seems content in their situation, but still provide Liz with all they can in an effort to better her life.

Despite ABA therapy (Lovaas, 1991), and a loving family, Liz still has many of the characteristics associated with autism. Lyn must fix different meals for Liz. Her eating disorder, as described in core impairments (APA, 1994), consumes time, and is a source of stress for her mother. Coleman (1989), and Norton & Drew (1994) find that autistic children have an obsessive desire for the preservation of sameness. This is demonstrated by Liz’s persistence on wearing

the color of blue, and the daily struggle with shoes, socks, and hair. Tantrums, another common characteristic (APA, 1994), seem to be Liz's biggest behavioral problem causing Larry and Lyn considerable stress. On the positive side, Liz is beginning to develop peer relationships, although not developmentally appropriate. No literature was found on degrees of sibling interaction, only the effects of autism on normally developing siblings, and the lack of interaction (Sorenson, 1993). Liz was observed several times in confrontations with Laura over computer time.

Lyn and Larry agonize over Liz's future. Anxiety about the future, especially concerns about the child's adult years is a source of deep despair for parents (Sanders & Morgan, 1997). This source of despair is often present throughout the life of the child, and may intensify as parents reflect on their own mortality, and the effects their death may have on their autistic child (Wickler, 1981). Lyn stated her thoughts, before the diagnosis, about where Liz would go to college, and wondered what her child would be when she grew up. After the diagnosis her hopes and dreams were shattered. Parents often fantasize about how their child will look and act, projecting their own hopes and dreams onto the child. When parents learn their child has autism, and come to accept the diagnosis and its implications, they begin the process of mourning. Burke, Hainsworth, Eakes, and Lingren (1992) refer to this type of mourning as chronic sorrow. Boss (1999) refers to this type of mourning as ambiguous loss, and maintains it is the most devastating of all the stressors related to autism because it remains unclear, indeterminate, and life-long.

Coping

Lyn and Larry have acquired skills and knowledge in their struggle with autism. They also acquired the confidence that they can use these competencies to solve problems and create a desirable and productive environment for their child's development. As families do well so does their autistic child (Fox, Dunlap, & Philbrick, 1997; Robbins, Dunlap, & Plienis, 1991). They have the skills to interact pleasantly, and productively. This ability is crucial among family members and essential in interactions with caregivers, teachers, friends, and support providers (Dunlap & Fox, 1999).

Success in adjusting their expectations for Liz has lessened stress on the family. They have successfully changed their expectations as evident by several statements by Lyn. For example, Lyn talks about the thought transition from thinking about the college Liz will attend to thoughts about getting her into a normal kindergarten. Lyn states, "Our thoughts have gone from thinking about the future to just thinking about tomorrow."

Lyn and Larry also derive much joy in the "little things." Just watching their children play together, and having Liz interact with other children brought immeasurable joy to Lyn. Larry was ecstatic describing the joy he felt when Liz finally told his father, "Don't go," after many months of literally pushing him out of the door.

Family #6: Calm in Numbers

A Day

Jerry and Jane describe yesterday as uneventful. “We had kind of a take it easy day,” says Jerry. Jane, Jerry’s wife was out late with a friend, and Jerry took care of their children plus his niece, who was visiting. It took him longer than expected to get all “seven” kids to bed. The couple got up at 6:30 A. M. and started their weekend morning routine of fixing breakfast. “Pancakes and bacon is the normal Saturday breakfast,” says Jerry, “We have to start early so Jess can eat before he has to take his medicine at 7:30.” Jess is the couple’s 8-year-old autistic son. Jerry and Jane also have five other children ages 16, 7, 5, 3, and 1. They played with the kids for a while, and then decided to get them all “some fresh air”, and went grocery shopping. They also stopped by the local hobby shop for Soapbox Derby supplies.

After getting home, Jane prepared a late lunch, and made sure she gave Jess his 3:30 P. M. medicine dose. Later they had a light dinner, and then watched a video. They got everyone in bed by 10 P. M., but had to keep Jess up for his 11 P. M. dosage of medicine. “Everyone was testy, but that’s normal with six kids,” declares Jerry.

Jerry, age 39, is the sales manager for a local sports TV station, and Jane is a 39-year-old homemaker. They live in a middle-class Northern Virginia subdivision of moderate, neatly placed homes. The home is comfortable and neatly organized with a very large dining room table. Mom is constantly pouring juice, and Dad occasionally lifts an infant to his lap. Soapbox Derby cars, and

their parts cover the dining room table, and toys and games are all stacked nicely in one open room off the kitchen. The atmosphere is very calm and pleasant. Jess's siblings are well mannered and pleasant. McHale (1986) suggests that siblings in larger families seem to adjust better than siblings in smaller ones. Furthermore, he found that larger family size was associated with less embarrassment and fewer feelings of burdens for siblings. The 16-year-old does her homework on the sofa, and Jess is fixated by a movie; he doesn't notice other children entering or leaving the room. Jess is distant and non-verbal; I don't think he noticed I was there.

Experiences involving Jess that produced feelings of joy were the next topic of conversation. Jane starts, "Swimming, going swimming in my Dad's pool, or going to the amusement park. He loves the rides, and he is wild about the water." Jerry hesitates for quite some time, and declares, "Nothing that really stands out, it's the small things." Jerry continues, "Jess and I traveled together to a sports event. He got on the plane, and did fine at the hotel; they had a pool." "It was just the two of us together; we don't get a lot of those opportunities with six kids," explains Jerry.

The mood turns somber as Jane relates several situations that make her sad. "Today, for instance, he was sobbing for no apparent reason," she explains in a tearful voice. After a pause, Jane continues, "It's sad when you can't help him because he can't tell you what's wrong; it is so sad." Jane is also saddened by her son's inability to defend himself when he is the object of cruel remarks, or gets shoved while other children are playing. Jerry is saddened about Jess's

previous school situation. “His classroom really upset me; it was not a pleasant environment,” explains Jerry. “It (the class) was a bunch of kids with no direction, and a teacher that didn’t care. That’s the part that really made me sad,” laments Jerry.

Embarrassing experiences was the subject to be discussed next. Jane talked about her trips to McDonald’s, and Jess’s uncontrollable urge to take French fries from every person they passed. Jerry’s experience with Jess and Special Olympics was very embarrassing for him. Jess was to participate in a swimming event. “They were really trying to have this structured event with real competition,” explained Jerry. “Jess didn’t understand,” says Jerry, “he just wanted to be in the water.” “I would get him out, turn my back, and he would be back in the water, even people from Special Olympics didn’t understand,” Jerry says with a look of bewilderment on his face.

As the conversation meandered, Jerry and Jane began talking about deep-seated feelings. “Living with an autistic child is an evolution; first it is hard to accept it, but with time you learn to accept it,” explains Jerry. He continues, “Now we have learned to accept him for what he is, still knowing we are doing everything we can to get him a better life.” “Thinking about the future is tough; we try not to; it’s pretty intense,” concludes Jerry. Jane picks up where Jerry left off, “We try everything we can for Jess; secretin, relation; you put your hopes and dreams in these things, and then you are crushed when they don’t work.” In the autistic community you often hear of miracle stories, and promising cures. “You hear about the miracles, and you want to be one of them,” explains Jane.

She tearfully continues, “Even if he looked at me, and said “Mom,” that would be enough right now.” Jess was potty trained at age 7. “That was the happiest day of my life,” exclaims Jane. “Between us and the therapists we spent 40 hours in the bathroom with him nonstop, except when he slept,” Jane says proudly.

“Any outing is stressful with six kids.”

Jerry and Jane packed up the kids and went for an outing to the Baltimore Aquarium. “Any outing is stressful with six kids; we are always in a constant mode of where everybody is at,” explains Jerry. Jess did fine except for his aimless wandering. “Jess wanders, but no more than the two-year-old,” says Jerry. He continues, “I guess that’s the problem; he’s eight, but still requires the maintenance of a two-year-old.” Jane speaks up, “I think it makes it easier having a lot of kids; all of our focus isn’t on one kid; it’s not all we think about.”

After going to the aquarium, the whole family visits Jane’s sister, who lives near Baltimore. Jane’s sister has four children around the same ages as Jane’s. Over the years they have become familiar with autism, and now are comfortable around Jess. “At first it was tense,” explains Jerry, “but now it’s OK.” “We just try to forge through, and not let it (autism) keep us from family and friends,” declares Jerry.

Structural Implications

As was suggested by McHale (1986), Mates (1990), and Featherstone (1982) a number of factors, such as family relationships, marital satisfaction, the parental ability to communicate to the normal siblings about the impairment, and the severity of the impairment all play a role in determining sibling well-

being. The apparent ability for this family to live well is also attributed to family size (McHale, 1986).

Jess is afflicted with many autistic characteristics. Norton and Drew (1994) emphasize communication as a major concern. Jess is unresponsive verbally. This is very upsetting to Jane during Jess's sobbing spells because "he can't tell you what's wrong; it's so sad," Jane says. Jess is quiet and distant; he seems trapped in his own world. There are no facial expressions (APA, 1994), only an empty gaze. According to the DSM-IV (APA, 1994), Jess suffers with the characteristics in every category of impairment. They are (a) impairment in social interaction, (b) impairment in communication, and (c) impairments in patterns of behavior. In addition to the 3 core areas of impairment required for the diagnosis of autism, the DSM-IV outlines a number of other characteristics that Jess possesses. They are (a) abnormalities in eating, (b) giggling or weeping spells, (c) no emotion when it is warranted, (d) lack of fear or excessive fear, and (e) fascination with certain stimuli.

Anxiety about the future is a large stressor on this family. Jerry tries not to dwell, but is obviously concerned about the finances of his family. Studies by Rodrique (1992), and Plienis, Robbins, & Dunlap (1988) report significant concerns about the availability and adequacy of financial resources. Parents in this study reported significant concerns about the financial costs incurred secondary to raising an autistic child, and whether family income was sufficient to cover the child's current and future expenses. In Jess's case these expenses include special schooling, therapy, and medical services. Jerry not only expresses

concern about the present, but also about the future. Unlike normally developing children, who usually achieve financial independence, most children with autism require long-term financial resources. Most autistic children will remain dependent all their lives (Bouma & Schweitzer, 1990).

Despite the family's effort to "forge ahead," in relation to family outings, Jess does have an effect on them. Jerry states, "Over the years they (Jane's family) have become familiar with autism, and are now comfortable around Jess." This indicates that relationships require a lot of time and energy to build when autism is involved.

Coping

Both parents are calm, and confident in their parenting skills. Parental competency is crucial in providing a productive environment (Dunlap & Fox, 1999). Family breakfast, Soapbox Derby activities, is evidence of family unity and interaction.

Jerry termed living with an autistic child "an evolution." They have come to accept Jess for who he is, not what they had hoped he would be. Jane and Jerry obviously have hopes for Jess's recovery, as evidenced by their attempts at medical intervention, and are disappointed when there are no favorable results. However, they remain committed to ABA therapy to help with Jess's behavioral problems to lessen the effects of autism on Jess and themselves.

Again, as with the other families, expectation adjustment is playing a crucial role in family adjustment and adaptation. Jane's miracle would be the day her 8-year-old son would look at her and say "Mom." The happiest day of Jane's

life was the day Jess was potty trained at age seven. These “little things” most parents of normally developing children take for granted are life events for parents of autistic children.

Summary

Chapter IV has produced a textural and structural account of six families' experiences of life with their autistic child. In Chapter V the six cases discussed in Chapter IV are brought together by analyzing common themes, and differences in each family. Through this means a synthesis of meanings and essences of living with an autistic child are produced.

Chapter V: Summary and Synthesis of Meanings

Summary of Data Collection and Analysis

Collecting data for this study was both exhilarating, and emotionally draining. This study produced joy, and sorrow. The interviews were like riding a roller coaster, taking all emotions to their extremes. The interviews took on a therapeutic nature for the interviewees and the interviewer. Talking to these parents reaffirmed my belief that I am experiencing something special that is making my life more complete. Is this what motivates parents of autistic children to carry on, to be happy, to be productive?

In analyzing the data a phenomenological model modified by Moustakas (1994) was used, and began with considering each statement from the transcript with respect to significance for the description of the experience. All relevant statements to the experience were coded as free nodes using NVivo Qualitative Research Software. After looking at all free nodes, all nonrepetitive, nonoverlapping statements were listed. These are the meaning units of the experience. The meaning units were then clustered into themes, which became tree nodes, and their related child and sibling nodes. The meaning units and themes were then synthesized into a *description of the textures of the experience*. When reading A Day, Emotions, and Family Outings in families 1 thru 6, you were reading a *description of the textures of the experience*. After reflecting on the textural description you begin to construct a *description of the structures of the experience*. This description was written in the sections titled Structural Implications, and Coping. What will follow is a *composite textural-structural*

description of the meanings and essences of the experiences. This integrates all individual textural-structural descriptions into a universal description of the experience representing the group as a whole.

Synthesis of Meanings and Essences

Action and Reaction

Each family interviewed for this study reacted differently toward the stress caused by their autistic child. Indeed, all families were affected in varying degrees. Furthermore, all autistic children in this study were different. They did share many common characteristics of autism, but in varying degrees. Action, and reaction were the thoughts that kept surfacing in my mind. The action being the child's behaviors, and the reactions to the behaviors by the parents. The amount of visible stress experienced by the parents seemed directly related to how severe the behaviors of the child were. In the cases of Family #2 (Bill, Betty, Bart, and Barbara), and Family #4 (Amy, Archie, and Andy) the autistic child's behaviors were severe. Bart constantly, and loudly, babbles. Bart also tantrums in public settings such as the grocery store, or the hair cuttery. Andy is very intense in his constant demand for attention. From the time his mother arrives home until bedtime Andy persists in uncontrollable fits of yelling and screaming. Family #2 and Family #4 are experiencing life with an autistic child in a difficult way. Betty finishes the interview with this statement, "I wonder when my batteries are going to run out; is he (Bart) ever going to be easier to deal with?" Amy sums up saying, "Sometimes I don't think I'm going to make it, I get so angry."

On the other hand, the families, in which the autistic child had less severe behaviors, seemed more relaxed, and had few negative comments. There comments were more directed at their feelings for their child, and the child's well being. They were generally happy with their lives, and enjoyed their child. They were also much quicker remembering joyous occasions, and situations, which produced laughter. Even while describing stressful experiences, the love for their child remained the focus. For example, Jill (Family #1), after describing a disastrous Christmas Eve, says, "I felt sorry for Jimmy." Jill summed up her interview by saying, "This isn't the way life was supposed to be; we planned our lives together; we had a route; the diagnosis made us miss our exit; now we just have to find a new way." Families #1, 3, 5, and 6 all had this general outlook on their situation. Comments extracted from these families include: "I thank God for his progress everyday," and, "We have accepted him for who he is." These families also persist in the process of normalization. That is to say they don't give up trying to make themselves and their child "fit in." Family #3 persists in taking Mike swimming, skiing, and to Disneyland not knowing what his reaction might be. Mitch admitted his apprehension about repeatedly taking Mike on outings stating, "You never know how he (Mike) is going to react," but they keep trying. Family #5 continually involves their daughter, Liz, in birthday parties, and cruise vacations. Jerry from Family #6 remarks, "We just try to forge through, we don't let it (autism) keep us from family and friends."

Action and reaction is not found in the current literature. Action and reaction is described as a stressor caused by a behavior. However, as noted

above, all behaviors do not cause stress. Some behaviors produced a coping reaction. Furthermore, the behaviors that did cause a parental stress reaction behavior may be a learned response to the child's behavior, perpetuating the child's behavior. The parent's reaction is so predictable and constant that it acts as a familiar, comforting reinforcement of the very behavior the parents wish to extinguish.

Grieving

After the diagnosis of autism, and when parents realize major milestones in development are passing their child by, ambiguous loss (Boss, 1999) sets in. According to Boss, this form of grief is the most devastating grief a parent can experience. This grief can cause some parents to spiral deeper, and deeper into depression, or it can trigger immense personal growth. All the families in this study experienced this form of grief. Jack from Family #1 gives this description, "A permanent sorrow that I carry with me that is never far from the surface." He also explains his feelings while driving home after the diagnosis saying, " It felt like I was in mourning, my hopes and dreams for Jimmy and myself died on the day of the diagnosis." Bill from Family #2 is constantly comparing his son to other normally developing children. He states, " I am always conscious, particularly when he is with other kids his own age, how striking the differences are." Comparing developmental milestones is a recipe for sorrow. Family #3 laments over the "family time lost" due to Mike's autism, and feels like important, developmental time is slipping away. Family #4 is continually frustrated by their futile attempts of putting Andy into a normal school

environment. Lyn from Family #5 sums up her sorrow by saying, “I usually cry when I put Liz to bed. She is such a sweetheart; my heart aches for her; I just want her to be alright.” Jane from Family #6 expresses her sorrow, “Even if he looked at me, and said, “Mom,” that would be enough right now.”

The ambiguity of autism confounds the grieving process. A child (Family #2) can learn songs, yet cannot feed himself. A child (Family #3) does well on a computer, yet cannot understand that hanging from a gutter is life threatening. A child (Family #5) is precious, and loving, but cannot understand why she is not invited to birthday parties. Seeing a child excel in a situation, and the next minute fail miserably is a constant, lifelong reminder of what the child is and, what the child might have been.

The data analysis on grieving agrees in general with reports from Boss (1999) and Burke, Hainsworth, Eakes, & Lindgren (1992) on ambiguous loss. *However, what is missing from the literature are the deep, descriptive, first hand accounts of mourning this study provides.* The deep grief felt by the parents of the autistic children was evident in every case. They understand their child will not experience life as they have. The thoughts were deeply descriptive, and heartfelt. Their question of “what if” will remain unanswered. Their hope for love, marriage, and children for their autistic child is dim. In some cases the parents will never know if their child is happy or sad, or if the child even realizes they are his/her parents. This study has produced a deep look into the questions these parents ask themselves everyday, and the resulting profound sadness caused by the inability to answer the questions.

Anxiety About the Future

All participants expressed concerns about the future. Family #1 expressed deep concern about what would happen to Jimmy when they were unable to care for him later in their lives. Family #2 is fearful that the future holds the same intense lifestyle that they experience now. Betty says, for example, “will he (Bart) ever get easier to deal with?” Family #3 openly expressed little concern for the future, even when the subject was probed. I believe they have mastered the art of living in the present. The coping strategy of living in the future will be discussed later in the chapter. Family #4 survives day-to-day, but their concerns are with being able to keep their family together. The parents share a mutual resentment towards each other. Amy, and Archie seldom spend time together with Andy. They also seemed much more comfortable when one of them had to leave the room to attend Andy. Archie made the comment that life was much easier when he was on business trips. Family #5 shares one common future concern. That concern is for their autistic child, and how she (Liz) will experience life. They want her future to be filled with wonderful memories, and they want her to have the opportunity to experience life as they have. Family #6, having six children, expressed financial concerns about the future. “Raising six children on one income is stressful enough, but then add an additional \$30,000 a year for Jess’s therapy, and it just doesn’t add up,” explained Jerry. He then summed up, “Thinking about the future is tough; we try not to; it’s pretty intense.” Experiencing the intense lifestyle providing constant care for their autistic child, and realizing their lives, and their child’s may be this way until they can no

longer care for their child creates anxiety, and pessimism about the future. They see their friends, and family raise their children, while comfortably realizing they will someday grow up to take care of themselves, and leave their parents, who will resume a normal life without children. The families in this study see a different future filled with intense care for their autistic child. They cannot look forward to a peaceful, relaxing retirement. Families who have learned, or are attempting to learn to adjust their thoughts, and literally live day-to-day seemed less prone to anger, and depression. The coping strategy of adjusting thoughts from future to present will be discussed later in the chapter.

The anxiety takes two forms. First, is the concern for the child's future. Will he/she be taken care of after the parents are unable to provide care, or are deceased? Will the child have a good life? Will the child ever be able to take care of itself? Second, is the concern for their (parents) future. Will life always be this intense, and can we manage it for the rest of our lives? Will we have a normal retirement? Can we financially support the family? Will the siblings develop normally? Will the siblings resent us, and their autistic sibling? There are no crystal balls. The parents have no answers to these difficult questions.

This study points out that the families not only had concerns about their autistic child's future, but also had even more concerns about their future. The looming thought: these families will never be independent of their autistic child. That is a very powerful statement that hits home to all families of autistic children. This study adds richness and depth to the studies of Koegel (1992) and Holroyd & McArthur (1976) when they determined that a leading source of

anxiety for parents was the concern with the long-term burden of parenting an autistic child.

Spousal Support

With the exception of Family #4, varying degrees of spousal support were evident, and played a large role in the stability of the household. Working together as a family is essential in encouraging normal family development. Teamwork was obvious in all families, again with the exception of Family #4. Family #4 used their Aupair to fill a lot of the gaps in their parental responsibilities. Two families (#1 & #6) had one parent at home, and the other worked. No resentment was noted. In fact, the spouses of these two women deeply admired them for taking on such a demanding job. Two of the families (#2 & #5) had one parent reducing their workload to spend more time at home. While some resentment was noted in Family #2, the situation was stabilizing. The resentment for Betty was not towards her spouse, but in watching others get promoted ahead of her. In Family #3 both parents worked long hours, and used a Nanny, and therapists to fill some of the void. On the weekends, and evenings, however, they preferred the company of their children, and each other, and shared in their parental duties. Family #4 showed no parental, or family cooperation. Amy states angrily, "Archie is always away; he (Andy) is worse then. I have to hold his head, and tell him to stop the craziness." In another instance Andy was relentless, chasing his mother around, and screaming while she was on the phone. Archie made a half-hearted attempt to stop him. His

quote, “I tried to distract Andy while Amy was on the phone, but it didn’t work. He just prefers his Mom.”

The sharing of parental duties, spousal communication about their feelings concerning their autistic child, a mutual respect for one another, and the acknowledgement of each other’s daily accomplishments clearly allow a pathway for proper family development. Spouses should never lose sight of the fact that they should complement each other, not work against each other. An autistic child, as demonstrated by the data, can divide a family, both physically, and emotionally. The parents must remain a team.

This study differs, concerning spousal support, from earlier studies by Milgram and Atzil (1988), Konstantareas (1989), and Konstantareas, Homatidis, and Plowright (1992). They reported that parenting burdens, concerning the autistic child, were not shared equally between the mother and father, with mothers assuming most of the responsibility. They also reported feelings of resentment by the mother, and portrayed mothers as always insisting that the fathers do more. This study indicates that whoever assumed the majority of responsibilities the other spouse admired and respected them for it, and made extensive efforts to assume responsibilities on weekends and evenings.

Support Systems

Unlike families with normally developing children, families with an autistic child must rely on specialized support systems adding to the daily stress of raising a family, including the autistic child. All of the families interviewed for this study take on the financial burden of a *behavioral therapy program* called ABA.

Per year, this therapy costs the families \$28,000 to \$45,000, and is not subsidized by insurance, or governmental agencies. In addition, yearly IEP battles are fought for the proper placement of their autistic child in our school systems. That is assuming there is proper placement. Some of the families did not have access to appropriate placement. For them an additional cost was absorbed for *private schooling*.

All of the families, with the exception of Family #5, and #6 had no local extended family for *respite support*. Even though Family #5, and #6 had local extended family neither used those family members to any great extent for respite care. Family #1 preferred no support saying, “We don’t generally go out by ourselves (parents). No one really understands his needs, or routine, except maybe his grandmother.” When the grandparents offered to move closer they declined explaining, “It would be nice to go out once in a while, but the tradeoff would be very time-consuming.” Family #2, with exception of having a nanny while they work, utilizes no respite care. When Betty’s parents made one of their infrequent visits last Christmas, Betty, and Bill were very uncomfortable. Betty states, “I love my family, but I don’t think they get it. It is hard when they come.” Family #3, also with the exception of a nanny, while they work, utilizes no respite care. They also feel uncomfortable around their extended family. Mary made many comments on how uncomfortable Mike (autistic child) made both her, and Mitch’s families feel, and the resulting resentment she felt towards her family. Family #4 has an AuPair whom they use extensively due to their long working hours. They have no viable extended family, with the exception of

Archie's sister, whom they seldom see, and Archie's aged father in Florida. Family #5 has local extended family, which they often visit with, but do not use for respite care. Lyn explains, "We just don't trust a high school kid, and we don't like to impose on our family." Family #6 has local extended family, but does not use them for respite care. They too feel slightly uncomfortable around extended family claiming, "Our family feels uncomfortable around our son."

While studies by Sanders and Morgan (1997), Norton and Drew (1994), Dunlap and Fox (1999), and Sharpley, Bitsika, and Efremidis (1997) emphasize the need for support and respite care, *this study* produced three themes that trickle down to the reason these parents *prefer no respite care*, even though it is available to some extent. First, the parents think they are imposing on their extended family members. Second, they do not trust the competencies of others to attend their autistic child. Third, and probably most important, these families do not feel that family, or friends understand the experience of living with an autistic child. They have little in common with families of normally developing children. For them, the daily life stressors we all share are compounded by autism. It leaves little time for patience.

Social Withdrawal

"We don't go out much as a family. It just isn't worth the hassle," a quote by Betty from Family #2 seems to sum up the general feelings about social activities from all the families. Some do forge ahead, but do describe most of their social family outings as stressful. Quotes about family outings from the families included: "The apprehension (about behaviors) caused a lot of anxiety,"

and, “Mike was scared to death, and freaked out,” and, “We tried to pin him in a booth, that works the best,” and, “She (Liz) tried to console the baby crying in the next booth, but the mother got a little nervous,” and, “That was stressful; he (Jess) wanders a little.”

This study reflects the views held by Gray (1993), Rodrigue (1992), Haefele and Henggler (1983), Lyle (1992), and Sanders and Morgan (1997) on social withdrawal. This study does provide descriptive examples of the different ways social withdrawal may manifest itself.

Embarrassment about the child’s behaviors, and the intensity of having to attend to the autistic child constantly are obvious reasons for social withdrawal. Some families have given up, some forge ahead, but all use a strategy explained in the next section.

Divide and Conquer

All families displayed a unique strategy to accomplish evening or weekend outings, and chores. I will call it divide and conquer. The strategy is used by all of the interviewed families except Family #1, and Family #4. Neither of these families needs to use divide and conquer because the autistic child has no siblings. The strategy is this: One parent takes the normally developing sibling(s) on an outing, or an errand, and one parent stays at home, or goes on an outing, or errand with the autistic child. Family #2 states, “Since there are two of them, and two of us we split up, and take Bart to the easier places where he will not be a problem.” Family #3 (Mitch) comments, “Separation of Mike, and Martha is very typical. I end up doing separate things with each of my children,

because Mike can't do things Martha can." Family #5 (Larry) said, "I took Laura to a birthday party, and Lyn took Liz shopping. We try to make it even." Jane (Family #6) does most of her outings, and errands while Jess is in school, or in therapy.

This strategy has evolved out of the need to (a) get errands done quickly and efficiently, and (b) to spend "normal" time with the siblings of the autistic child, without feeling the anxiety of the constant attention the autistic child must be given.

Rodrigue (1992) briefly mentions fewer husband-wife activities. *This study* points out that the practice of "divide and conquer" is a common occurrence among the families in this study, and is a major concern for these parents. Although "divide and conquer" may be a coping mechanism it acts as another wedge separating these families from normal family life.

Anger

Living with an autistic child is an intense, lifelong journey. The first devastating jolt is the diagnosis of autism. Although most parents suspected something was wrong with their child, the true shock of the reality of autism accompanied the diagnosis. After the initial trauma wore off we began to see the differences in the families. Anger is an emotion that all people experience in their lives; however, parents that have an autistic child experience anger generated by autism itself. Obtaining services for their child is a daily struggle. Rejection by society, the school system, their neighborhood, and in some cases their families fuel their anger. For the most part their anger is directed toward the doctors who

offer no treatment, the school system that offers no services, autism itself, or other people. Family #4 tended to turn their anger toward their autistic child, and at each other. Amy, while tears of anger flowed down her cheeks, declared, “When Andy is out of control, usually when Archie is out of town, it’s almost unbearable. Sometimes I get so angry I don’t think I’m going to make it.” Archie is outraged by Andy’s obsessive-compulsive behaviors. “Fighting those battles really hacks you off,” Archie explained.

At times during the interviews it seemed that anger and sorrow existed in one emotion. For example, Family #1 relayed an experience in which a neighbor boy told Jimmy he talked really weird. She said, “I was angry at the situation. I was angry at autism. How many times will he face these situations?” Bill (Family #2) described a situation at a coffee shop in which he wanted to tell everyone there to “stick it.” Then he felt sorrow for himself saying, “If they had to deal with what I have to deal with, maybe they would be a little more tolerant.” Mary (Family #3) was angry with a ski guard for confronting her on how she was trying to control her son’s behavior on the ski slopes. After her outburst of anger she said to me in a hurt voice, “He questioned my ability as a mother.” Family #4 felt angry, confused, and sad when Liz’s diagnosis was delivered in an insensitive way. Jane (Family #6) claimed anger at a bad teacher, and a bad school environment. Her ending quote on that experience, however, was said in a sullen voice, “It felt like we lost two years of time for Jess.”

While McHale, Sloan, and Simeonsson (1984) and Carr (1985) reported on sibling feelings of anger toward their autistic brother or sister, no literature was

found that reported parental feelings of anger toward their autistic child, at situations caused by autism, or at agencies servicing their autistic child. *This study* has provided data that suggests these forms of anger do exist in families with an autistic child.

Interaction and Avoidance

This study also provides information about another previously unmentioned theme, that of interaction and avoidance. While the families were actively involved with their child to provide the best possible life for them and the family, some showed signs of avoidance by working long hours, and letting their child become fixated on seemingly meaningless activities. Avoidance does not mean they do not love their child. Avoidance means they cannot cope with the situation at home. These parents spend \$30K to \$40K per year on behavioral therapy. Some have mortgaged their homes, and borrowed large sums of money. They both care for, and love their children as evidenced by the extreme showing of emotions throughout the interviews.

Interaction comes in two levels. First, is the day-to-day parent-child interaction. This type of interaction is playful, and engaging, which is essential in building a bond with the autistic child. Second, is the inclusion of the autistic child as part of the family. Somehow it seemed strange, even though I am a parent of an autistic child, to hear families talk about their autistic child so differently from their other children. Families, seemingly, tended to look at their child as an extension of their family, instead of part of the total family. This is not

a negative statement, merely an observation of family's different perspectives on their experience.

Embarrassment

Embarrassment in social settings was common in all families. Their autistic child's behaviors caused all the families to be socially isolated in varying degrees. All the families attributed their embarrassment to bizarre behaviors, and/or rejection of their child by their peers. There were several descriptions of grocery store tantrums, taking food from stranger's plates in restaurants, haircut tantrums, and tantrums in other public places such as Disneyland. Family #2 seemed to sum up the general feeling of most of the families saying, "It just isn't worth the hassle."

This study agrees and augments studies by Gray (1993), and Sanders and Morgan (1997) concerning embarrassment caused by the behaviors of autism. *What could be the real reason, though, that causes the parent's embarrassment?* As I lay in bed one night pondering the data, the reason for the extreme embarrassment became clear. Because autism has no physical abnormalities, the child's behavior caused the parents to assume that others would perceive the child's behavior as a reflection upon their parenting abilities. For example, Betty from Family #2 describes a visit to a grocery store where Bart has a "meltdown." She explains, "I get weird looks from everyone, I'm sure they think he is just a brat, screaming, and yelling." Family #1 describes a similar situation. Family #3 referred to a situation in a museum. The security guard approached them after Mike explodes. Not knowing Mike was autistic the security guard begins questioning

Mike, who cannot answer him, as to whether Mary was his mother. Family #4 describes a normal looking child who grabs French fries off stranger's plates in restaurants, as does Family #6. Family #5 describes a normal looking child who "loses it" every time they leave a place she does not want to leave. Their only defense against embarrassment is a 15 to 30 minute oration on autism.

Profound Sadness

All families expressed profound sadness involving experiences with their autistic child. None had problems recalling many specific incidences. The sadness, however, seems to be connected to ambiguous loss, and behaviors. Specifically, not seeing their children as fitting in, or reaching certain developmental milestones.

This study has produced the notion that the sadness is produced by daily events that may remind the family of their plight, while grieving, as described by Boss (1999), is a product of the lifelong perception of the life of their autistic child. For example, Family #1 described a devastating Christmas Eve when Jimmy could not be around so many people, and escaped to the basement. Family #2 was saddened by the thought of Bart not attending college. Family #3 described the very frightening experience of Mike hanging on a gutter 3 stories up. In this case Mitch was saddened by his own actions of not securing the room. Family #4 was saddened by Andy's inability to fit in developmentally at birthday parties. Family #5 describes a situation, in which Liz is not invited to a birthday party, and her sister was. Laura comments, "How many times will she be left out?" Family #6 was saddened by the inability to comfort their son during

sobbing spells. These experiences drive home the fact, and make it readily apparent that their child is different. These experiences, and many like them, occur on a daily basis.

Consuming Thoughts

All families expressed deep emotions caused by their autistic child. Again *this study* deeply illuminated this obsessive thought processes these families experienced. Most families expressed all-consuming, constant thoughts of their child. Most admitted that not a minute goes by without thinking of their autistic child, and being filled with overwhelming sadness. The ease in which different experiences were recalled, quickly, and in detail, give credence to the fact that thoughts of their autistic child are always present. School experiences seemed a constant source of thoughts of frustration and sadness. They were generally daily struggles trying to get proper placement, and getting the services they needed. Experiences and thoughts were intensely relayed, and easily recalled by the participants. Family #1 (Jack) states, “When I wake up in the morning my first thought is Jimmy.” Family #2 (Betty) says, “I constantly think about Bart’s future. I stay depressed for long periods.” Family #3 (Mitch) states, “I feel responsible for Mike’s accidents, so now I never take my thoughts, or my eyes off of him.” Family #4 (Archie) reveals, “I constantly think about his bad behavior in school. It is a source of constant frustration.” Family #5 (Lyn) states, “There is hardly a minute goes by that I am not thinking of Liz, and how she is doing. She is always on my mind.”

Intensity

The intensity of living with an autistic child stems from a number of sources. First, is the special services the autistic child requires. This list gathered from the participants in this study includes behavioral therapy, medications, special needs school programs, and special diets. Second, is the constant supervision required to ensure the child's safety. All autistic children in this study had no comprehension of direction if lost, or fear of dangerous situations. Third, is the extra energy parents must expend to face sleepless nights, and enduring bizarre behaviors. Raising an autistic child for the parents in this study was indeed a 24 hour, 7 days a week labor of love.

This study reinforces the findings of Coggins and Frederickson (1988) on the relentless nature of the symptoms of autism.

Living in the Present

Learning, with some success, to live in the present, shifting your thoughts from the long term to the short term seemed to provide stress relief for the families, again in varying degrees. Families #1, #2, #3, #5, and #6 commented on this process. Family #1 (Jack) said, "My thoughts have turned from getting their child into college, to getting him into kindergarten." Also in Family #1, Jill states, "I have learned to live life one day at a time." Betty (Family #2) states, "Thinking about the future is very depressing. I really try to focus on today." Family #3 seemed to be the most successful not dwelling on the future. Future thoughts were not mentioned during the entire interview. Family #4 lives such an intense lifestyle I doubt they have the time, or energy to ponder the future. Their main

concern is surviving each passing day. Lyn (Family #5) states, “Our focus has gone from future hopes, to hopes for tomorrow. Jerry (Family #6) simply states, “Thinking about the future is tough, we try not to. It’s pretty intense.”

The coping mechanism of living in the present uncovered by *this study* was not discussed in any of the literature reviewed for this study.

Adjusted Expectations and the “Little Things”

All of the participants were middle-class, Caucasian, two parent households. The differences seen between the families, especially the extremes in anger, and calmness must also lay in the parents learned coping mechanisms that reduce stress produced by the autistic child’s behaviors. This includes their use of resources such as respite care, financial planning, and therapy. These are all buffers against stress. Interpersonal coping strategies such as parent confidence and competency to secure the most influential resources for their autistic child, as discussed by Fox, Dunlap, and Philbrick (1997), Robbins, Dunlap, and Plienis (1991), and Bailey, Simeonsson, and Winton (1986) are critical. *Not discussed*, however, in the reviewed literature is the parents ability to learn to *adjust their expectations*, to learn to accept their autistic child for who they are (and appreciating it), and being able to find joy in the “*little things*” seem to be, according to *this study*, most valuable tools in coping with an autistic child, and their behaviors.

The most remarkable emotion explored by this study was that of *joy*. Remarkable because of how it was found, and interpreted. “Little things” such as jumping into a pool, knowing the words to a song, writing a name without help

at age seven, a hug, and seeing your child play with other kids were the most joyous, and memorable occasions in the participant's lives. The ability to *adjust expectations* so these events are joyous, and memorable, however inappropriate developmentally speaking, is a remarkable tribute to the participants of this study. The "little things" allowed the parents of autistic children in this study to experience happiness. Happiness, joy, and even the simple act of smiling have long been known to be a source of stress relief. Learning how to use the coping mechanism of adjusting expectations allowed the families to cope, in varying degrees, with some of the hardships this devastating disease brings.

Ambiguity

This study clearly determines that living with an autistic child can be difficult, yet rewarding. Although the families don't consider the experience a blessing, one gets the impression that these families experience life on a deeper level. They experience life on two planes. The reality of life, and the ambiguous thoughts of what life could have been like. They are more aware of life's simple pleasures, and more thankful when life brings good tidings.

During the interviews tears were shed for their child, but many moments of laughter were shared as well. This is the bond that parents of autistic children share. When parents of normally developing children engage in conversation tears of sorrow are not usually shed, while tears are a normal part of the conversation involving the parents of autistic children. The situation is ambiguous. They experience joy, and sorrow from the same situation. The parents are overjoyed at the "little things," yet these very things display their

child's developmental differences. They love the child that is, but what about the child that was supposed to be.

This study agrees with Boss's (1999) findings on ambiguity, however, the study does shed some light on the insightful aspects of autism.

Future Research

During this study questions of interest emerged not intended to be answered by this study as catalyzed by observation in the process of the inquiry. One such topic was sibling interaction, and its effect on the family. Normally developing siblings interact on a daily basis. The interactions may vary from nice play to fighting. What effect does the lack of sibling interaction between an autistic child and his/her normally developing sibling have on both children's development? Another topic generating interest was set forth by the limitations of this study. The study gives an account of the experience of living with an autistic child from the perspective of Caucasian, two-parent, middle-income families. Future studies might include a more racially, and economically balanced sample for obvious reasons.

Another area of interest may be a more focused study on the functioning of the family system and its individuals prior to the diagnosis of autism, the impacts on the adaptivity/maladaptivity of their responses to the behaviors and implications, and the experiences thereby manifested. Spousal support, as reported by this study, differed from studies in the past. Milgram and Atzil (1988), and Konstantareas (1989) reported that most of the burden of raising an

autistic child fell to the mother. The reason why and how spouses engage in an equal partnership in raising their autistic child is a fertile terrain for future study.

In the area of interaction, interest was peaked as to the reason why parents tend to look at their autistic child as extensions of the family. Could it be the separate financial burden caused by the child, or the obvious differences from their normally developing children? Also captivating was the obvious difference in the levels of intensity experienced by the families. Some families were consumed by the intensity of living with an autistic child while others, although affected by the same implications, were better able to cope with the intensities. The placement of anger was also an area, which evoked future interest. Some were angry at autism itself, some were angered by support systems, and some were angry with their spouses and autistic child. How could anger manifest itself in so many different places by people who share the same experience?

In summary, all new themes produced by this study could merit further research. In the section below titled “New Knowledge Generated” I have listed the themes, according to my perception, in order of importance.

Enriching the Body of Knowledge

Introduction

This study has produced the notion that one cannot create broad generalities about how families are affected. This study has added to the body of knowledge by bringing attention to that very fact. There are many differences, large, and small. In response to each question, each participant’s experiences were different in some way. Also adding to the body of knowledge were the

feelings, thoughts, and emotions investigated in great depth by a researcher with a unique advantage in gathering data. These descriptions enriched and deepened the research reviewed in the current literature. While the rich description of all the themes enriched the current literature, some added new knowledge. The following two sections separate new knowledge and the enhancement of the current literature.

New Knowledge Generated

This study has uncovered new information about action and reaction, spousal support, support systems, “divide and conquer,” anger, interaction and avoidance, embarrassment, sadness, consuming thoughts, and a variety of coping mechanisms. These include; living in the present, “adjusted expectations,” and the “little things.” *In the section below titled New Knowledge Generated I have listed the themes, according to my perception, in order of importance. In addition, some themes manifested themselves as an internal reaction, while others as an observable physical reaction. Each theme will be noted as physical or internal.*

Divide and conquer is the finding that produced clarity to the ambiguous nature of having an autistic child. While the coping strategy of parents going separate ways (one parent with the autistic child and the other with the normally developing siblings) on errands, to dinner, to the movies, etc. allows them to get things done and spend separate time with normally developing siblings it also tears at the very essence of the family fabric. The strategy of divide and conquer was used by all participants in this study, and was an *observable, physical coping strategy*.

The ability for parents to *learn to live in the present* seemed essential in adapting to family life with autism. Every family made statements about how their future plans have changed to the present. Many statements were made such as, “My thoughts have turned from college to getting him into kindergarten,” and, “I have learned to live life one day at a time.” This study also indicated that the ability to *Adjust expectations* to appreciate the *little things* was the enabling factor that allowed these families to experience joy concerning their autistic child and was tied into learning to live in the present. *Learning to live in the present was an adjusted expectation*. Little things such as verbally recognizing a color at age 4, and simply jumping into a pool produced joy and a sense of pride in their child’s accomplishments. *Adjusted expectations, little things, and learning to live in the present were coping strategies which were internal, learned processes not clearly observable*.

Studies on *spousal support* by Milgram and Atzil (1988), Konstantareas (1989), and Konstantareas, Homatidis, and Plowright (1992) reported that parenting burdens, concerning the autistic child, are mainly the mothers’ responsibility. They also report feelings of resentment by the mother, and portrayed mothers as always insisting the fathers do more, however. This study indicates that responsibilities were shared by both parents. This study also indicates that the spouses had a mutual respect for the efforts each put into the rearing of the autistic child. This may be due to the changing attitude and times in which we live. *Spousal support, or lack there of, was a clearly observable coping strategy. Although some would include this theme within support systems I preferred to*

keep it separate. Spousal support was a constant, while other external support systems had to be acquired.

All families experienced *embarrassment* due to their child's bizarre behaviors. That is well documented in the literature. This study suggests that the nature of the embarrassment is due to the child's normal physical appearance. Because autism has no physical abnormalities parents assumed that others would perceive the child's behavior as a reflection upon their parenting abilities. *Embarrassment, although at times very observable, was a reaction that most parents learned to hide and carried the reaction internally.*

This study has also *separated grief from profound sadness*. Sadness was seemingly produced by daily events that may remind the family of their plight, such as the inability for their child to interact with other children, or attend school in a normally developing classroom. Grieving, as described by Boss (1999), is a product of the lifelong perception of the life of their autistic child. Knowing their child will not experience life as they had, and not knowing how their child will be taken care of after their death are examples of what causes the lifelong grieving process. *Grief and sadness were deeply rooted internal feelings, only observable after the topic surfaced during interviews.*

Made apparent by this study were the *all-consuming thoughts* about their autistic child. Most parents divulged that hardly a minute goes by without thoughts of their child. Thoughts about the child's future, about their safety, or how they are doing in school were some of the things that occupied the minds of the parents. *This theme was an internal implication.*

Studies by Sanders and Morgan (1997), Norton and Drew (1994), Dunlap and Fox (1999), and Sharpley, Bitsika, and Efremidis (1997) emphasize the need and use of support and *respite care*. While the families in this study did use the support agencies they seemed to prefer *no respite care*. The data produced three reasons they preferred no respite care. First, the parents thought they were imposing on their extended family members. Second, they did not trust the competencies of others to attend their autistic child. Third, these families do not feel that family or friends understand the experience of living with an autistic child. *Respite care, or the lack there of, was obviously observable.*

While studies by McHale, Sloan, and Simeonsson (1984) and Carr (1985) report sibling feelings of *anger* toward their autistic brother or sister, no literature was found that reported parental feelings of anger directed at their autistic child, at situations caused by autism, or at agencies servicing their autistic child. This study has provided data that suggests these forms of anger do exist in families with an autistic child. *Anger was also observable, however, the question for future research remains pertaining to the amount of internal hidden anger not displayed by the parents of the autistic children.*

This study has provided knowledge about another previously unmentioned theme, that of *interaction*. The first type of *interactions* observed were playful and engaging, which is essential in building a bond with the autistic child. The second, unmentioned in the current literature, was the tendency for the parents to talk about their autistic child so differently from their other children. They seemed to look at their autistic child as an extension of their

family rather than part of the whole family. *Interaction was both physically observable and detected in the parent's data as they talked about their children.*

Adding Richness and Depth to the Current Literature

Findings concerning grief, anxiety about the future, social withdrawal, intensity, and ambiguity all support the current literature. They do augment the current literature, however, by providing a rich, qualitative description. *Grief, anxiety about the future, ambiguity, and the intensity of living with and autistic child were thoughts and emotions buried internally not readily observable. Social withdrawal, however, was a physical reaction to the inappropriate behaviors of the autistic child and readily observable.*

This study has provided a vivid insight into the personal lives of families afflicted with autism, and knowledge, both new and enlightening, to allow us to have a better understanding of the “lived” experience, and what it means.

Appendix A: Summary of the Phenomenological Model

Adapted from Moustakas' Phenomenological Research Methods, 1994

Processes:

Epoche: Setting aside prejudgments and opening the research interview with an unbiased, receptive presence. Preparation for deriving new knowledge. To look at an experience as if seeing it for the first time.

Phenomenological Reduction:

1. Bracketing: The entire research process is rooted solely on the topic.
2. Horizontalizing: Every statement initially is treated as having equal value. Later, statements irrelevant to the topic, as well as those that are repetitive or overlapping are deleted leaving only the Horizons (the textural meanings and invariant constituents of the phenomenon).
3. Clustering the horizons into themes. Organizing the horizons and themes into a textural description of the phenomenon.
4. **Individual Textural Descriptions**: An integration, descriptively, of the invariant textural constituents and themes of each research participant.

Imaginative Variation: **(Individual Structural Descriptions)**

1. Possible structural meanings that underlie the textural meanings.
2. Recognize the underlying themes or contexts that account for the emergence of the phenomenon.
3. Consider the universal structures that precipitate feelings and

thoughts such as structure of time, space, bodily concerns, materiality, relation to self, and relation to others.

Synthesis of Composite Textural and Composite Structural Descriptions

An integration of textural and structural descriptions to develop a synthesis of the meanings and essences of the phenomenon or experience.

Written Structure of Each Family Description (Chapter IV)

A Day and Emotions (Textural Description)

Structural Implications and Coping (Structural Descriptions)

Chapter IV ends with a Composite Synthesis of Textural and Structural

Descriptions (Essence)

} **Individual
Families**

} **All
Families**

Appendix B: Letter to Participants

Date

Dear,

Thank you for your interest in my dissertation research on the experience of living with an autistic child. I value the unique contribution that you can make to my study and I am excited about your participation in it. The purpose of this letter is to reiterate some of the things we have already discussed and to secure your signatures on the participation- release form that you will find attached.

The research model I am using is a qualitative one through which I am seeking comprehensive depictions or descriptions of your experiences. In this way I hope to illuminate or answer my question: “What is the experience of living with an autistic child?”

Through your participation I hope to understand the essence of living with an autistic child as it reveals itself in your experiences. You will be asked to recall specific episodes, situations, or events that you experience as a parent of an autistic child. I am seeking vivid, accurate, and comprehensive portrayals of what these experiences were like for you: your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experiences. Understanding and drawing meaning from these experiences may help to educate families, extended families, friends, and professional caregivers effected by the devastation of autism.

I value your participation and thank you for the commitment of time, energy, and effort. If you have any further questions before signing the release form, I can be reached at home (703-481-3270) or by cell (703-864-0689).

With warm regards,

Paul W. Glass

Appendix C: Participant Release Agreement

Participant Release Agreement

I agree to participate in a research study titled Autism and the Family: A Qualitative Perspective. I understand the purpose and nature of this study and I am participating voluntarily. I grant permission for the data to be used in the process of completing a Ph.D. degree, including a dissertation and any other future publication. I understand that a synopsis of each participant, including myself, will be used to help the reader come to know and better understand each participant. Actual names will not be used to preserve confidentiality. I grant permission for personal information to be used in this confidential manor. I agree to meet at the following location _____
_____ on the following date _____ at _____ for an interview and observation period of up to 4 hours. If necessary I will be available at a mutually agreed upon time and place for an additional 1 hour interview. I also grant permission to tape-recording of the interview(s) and observational note taking.

Research Participant/Date

Researcher/Date

Research Participant/Date

Appendix D: Guided Interview and Questions

The phenomenological interview (Moustakas, 1994) involves an informal, interactive process, and utilizes open-ended comments and questions. The parents were interviewed together using this *guided interview* technique. The technique allowed information to surface as the interviewee recalled it, and/or allowed verbal spontaneous interaction between spouses to enrich experienced events or thoughts. The guided interview allowed the researcher the opportunity to probe, but also ensured that all pertinent topics were covered. The following are open-ended questions used by the researcher for this study:

1. Describe yesterday in complete detail from the time you woke up until you went to bed.
2. Describe a joyous experience involving your autistic child.
3. Describe an experience involving your autistic child that produced sorrowful emotions.
5. Describe an experience involving your autistic child that made you angry.
6. Describe an embarrassing experience involving your autistic child.
7. Describe your last social outing as a family.
8. Talk about the last visit with extended family.
9. Is there anything you wish to add that I have omitted?

Table 1: Family Demographics

	Family 1	Family 2	Family 3	Family 4	Family 5	Family 6
Age Mom	32	37	45	51	41	39
Age Dad	34	47	44	48	37	39
Age Aut. Child	Male 4	Male 5	Male 7	Male 7	Female 5	Male 8
Age Sib 1		Female 7	Female 8		Female 4	Male 1
Age Sib 2						Male 3
Age Sib 3						Male 5
Age Sib 4						Female 7
Age sib 5						Female16
Occupation M	Home	Analyst	Lawyer	Dir.HRD	Acct.Rep.	Home
Occupation D	Ins. Mgr.	Analyst	Lawyer	Lawyer	Engineer	Sale Dir.
Ext. Family Loc.	NY, NC	PA,FL,CT	MA,MD,FL	OH,FL,NY	Local	Local
Treatments?	ABA/Speech	ABA/Diet	ABA/Vita.	ABA	ABA	ABA/Kil.
Race	Cauc.	Cauc.	Cauc.	Cauc.	Cauc.	Cauc.
FamilyTherapy?	Yes/Dad	No	Yes/Sib 1	No	No	No
Respite Care?	No	No/Nan.	No/Nan.	No/AuP.	No	No
Residence in	No. VA					
Family Health	Good	Good	Good	Good	Good	Good

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Vita

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Paul W. Glass was born in Rochester, Pennsylvania on April 3, 1955. He was educated in the public schools of the Rochester Area School District. He earned a B.A. in Environmental Studies (1977), a B.S. in Secondary Education (1978), and a post-graduate certificate in Environmental Education (1979) from California State University in California, Pennsylvania. He received a Master's Degree in Human Development in 1999 at Virginia Polytechnic Institute and State University, and was accepted into the Human Development doctoral program in 1999. Paul Glass earned his doctorate degree in September of 2001.

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