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Autism and its Effects on the Family

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AUTISM AND ITS EFFECTS ON THE FAMILY

By

Adam M. Hutton

B.A. University of Maine, 1997

A THESIS

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Science

(in Human Development)

The Graduate School

The University of Maine

May, 2002

Advisory Committee:

Sandra L. Caron, Professor of Family Relations, Advisor

Betty Crossman, Supervisor of Autism Community Services, Penquis CAP

Gary Schilmoeller, Associate Professor of Child Development

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By Adam M. Hutton

Thesis Advisor: Dr. Sandra L. Caron

An Abstract of the Thesis Presented
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Degree of Master of Science
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The purpose of this study was to examine the impact of having a child with autism on the family. The study is comprised of a non-random sample of 21 families with children who have been diagnosed with autism. The parent who is the primary caregiver of these children was interviewed about recognition/diagnosis of autism in their child, services accessed, and the impact of having a child with autism on their family.

The results of these interviews suggest that families who have a child with autism share many of the same feels of frustration, stress, constant need for schedules, and also feelings of hope and goals for the future. Even after a diagnosis is made, that is just that start to a world that can be more about paperwork and waiting lists than a day at the park or a week's vacation. Once parents move past some of the feelings of sadness, guilt and trauma, they find themselves searching for services that can seem unobtainable. Even when services are found, there can be a lack of qualified people to fill the positions which leads to even more frustration.

It is often the family as a whole that is greatly affected by the diagnosis, whether it is the parent(s) running to an appointment for their child with autism or completing another piece of paperwork, or the aunt watching the child for a couple of hours so that the parents can have some time alone away from home. Implications for those working in the area of autism are discussed.

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Chapter 1

RESEARCH ON FAMILIES WITH CHILDREN WITH DISABILITIES

There has been a lot of research focusing on families with children with disabilities. A particular area of interest for researchers has been to examine the impact of having a child with a developmental disability such as Down's Syndrome or mental retardation. There is recognition that these families have unique experiences and challenges. As described below, much of the research has focused on the stress and coping abilities of these families.

Parents of a child with a disability experience more child-related stress than parents of typically developing children (Breslau & Davis, 1986; Duis, Summers, & Summers, 1997). The added daily stress from caring for a child with a disability has been found to result in low morale for roughly one-third of families (Singer et al., 1993). Interestingly, a parent's perceived level of stress has been found to be more directly related to the type and amount of social supports than the disability itself (McMillen, 1998).

Other studies have suggested that the stress in families with a child with a disability may be related to not only social support, but also to the coping ability/problem solving ability of the parents (Guess, 1998). For example, parents of 24 children with Down's Syndrome and other disabilities participated in a problem solving session. Those parents with better problem solving skills were found to have lower stress and better family functioning (Goldberg-Arnold, 1998).

Income has also been found to be related to stress in these families. Families with children with disabilities have an average income four to five thousand dollars lower per year and a divorce rate of approximately 20% vs. 15% for parents of typically developing children (Hodapp & Krasner, 1995). In a study of 880 families with children with disabilities, income and social support more accurately predicted parenting stress than aspects related to the child's functioning level (Smith, Oliver, & Innocenti, 2001).

Research has also found that family involvement in community activities is important not only for social integration and acceptance for the child, but for unification and support from other parents of children with disabilities. In a focus group with 21 families with at least one child with special needs (Freedman, Litchfield, & Warfield, 1995), it found that parents' most important source of emotional support was other families with children with special needs. Boyce, Behl, Mortensen, & Akers (1991) found that support from other parents, family cohesion, stressful life events, and community resources were the significant predictors of parent-related stress and coping. Despite the importance of such involvement, parents of children with disabilities have reported much lower participation in community activities (Ehrmann, Aeschleman, & Svanum, 1995). This lower level of community involvement appears to be partially due to significant behavior problems, and not always directly related to the disability (Floyd & Gallagher, 1997).

Research has also looked at the stress on mothers versus fathers of children with disabilities. Fathers have been found to experience similar levels of stress as mothers, but fathers' stresses are related to different aspects of the child's disability (Keller, 1999). Fathers reported having more difficulty with attachment to their child and to their role as

caregiver. Mothers experienced significant related stress as related to the child's behavior and care demands (Keller, 1999). Lillie (1993) found that fathers of children with disabilities want more involvement than previously thought. Fathers of children with special needs have been found to perceive programs for their children as structured toward female parent caregivers, and that fathers' efforts go without much notice or credit (Lillie, 1993). From these studies, it can be seen that fathers also experience many concerns and stresses and that they desire an increased role in parenting their child with special needs.

Chapter 2

LITERATURE REVIEW ON AUTISM IN CHILDREN

One specific disability in children that has received quite a bit of attention in recent years is autism. The word autism originated from the Greek word *autos*, meaning self, implying narrowing of relationships to the world (Janzen, 1996). Leo Kanner first coined the term autism in a clinical paper in 1943 describing eleven children with “autistic disturbances of affective contact.” Kanner’s work described the difficulties with socialization, communication difficulties, repetitious behaviors, and ineffective use of language (Kanner, 1943).

What is Autism?

Autism appears to be the result of a neurological disorder that affects the functioning of the brain and is estimated to occur in as many as 1 in 500 children (Centers for Disease Control and Prevention, November 16, 2001). It is found four times as often in boys than in girls and crosses all racial, social, and ethnic boundaries. Autism is a pervasive developmental disorder that is characterized by impairments in communication and social interaction, and restricted, repetitive and stereotypic patterns of behavior, interests, and activities (American Psychiatric Association, 1994).

Early on, possibly as early as the first few months of life, it is evident that children with autism may not engage in social behaviors such as eye contact, smiles, and responses to parent’s attempts to prompt vocal and play interactions. When language is learned, often at a late age, pragmatic skills such as initiating conversation and responding to the conversation of others may be lacking (Koegel, Koegel, Hurley, &

Freya, 1992). Appropriate turn-taking, speech detail, perseveration, and attention to tasks and surroundings may also be lacking (Koegel et al., 1992). Children with autism often have verbal deficiencies, self-stimulatory behaviors, aggressive or self-injurious behaviors, demand for sameness in environment, and inappropriate play (Koegel & Koegel, 1995).

Some children appear to develop normally for a period of time, then lose early communication and social skills or fail to develop more advanced language and social skills. Pediatricians, language and communication pathologists, and in some cases teachers, who may see children in clinical or classroom settings, can sometimes detect the indicators of autism as young as 12-18 months. In most cases, the indicators of early childhood autism are generally the most clear at age 2-3 (Janzen, 1996). Occasionally, the indicators of autism appear later after severe illness or accident such as encephalitis or traumatic brain injury (Gillberg, 1984).

What Causes Autism?

The true cause of autism is still unknown and continues to puzzle researchers. Many believe that genetic factors play a major role in the etiology of autism. Others believe it may be related to epilepsy or EEG abnormalities, blood flow to certain areas of the brain, the amount of serotonin found in the brain, or blood levels of gamma-aminobutyric acid (GABA). It should be noted that there has been little evidence to support such causes of autism as mother's exposure to drugs and alcohol, oxygen deprivation, lead exposure, or viral infections during pregnancy such as congenital rubella (Gillberg, 1990; Gillberg & Coleman, 1992), as well as any link to immunizations (Frombonne, 1999; Taylor et al., 1999) or levels of secretin (Corbett et al., 2001).

One of the leading theories on the causes of autism is genetics. Evidence suggests that genetic factors are likely to play a major role in the etiology of autism, and it is thought to be a complex collection of several genes that lead to autism in children (Maestrini, Marlow, Weeks, & Monaco, 1998; Young, Brasic & Levin, 1990). For example, in one study, it was found that as many as 7% of males with fragile-X syndrome (a genetic disability) also have autism, which supports the theory that genes are related to the occurrence of autism (Fisher et al., 1999). Several studies reinforcing the genetic link have focused on the incidence of autism in twins, noting a higher rate of autism in identical versus fraternal twins (Folstein & Rutter, 1978; Mizuno & Wakabayashi, 1977).

Studies have also shown an increased prevalence of both epilepsy and abnormal EEG activity in children with autism (Nass & Devinsky, 1999; Tuchman, 2000). There is some evidence to suggest that the use of anticonvulsants to treat epilepsy has had positive affects on language and behavior problems in children with children (Tuchman, 2000). Steroid therapy has also been offered as a means to treat possible autoimmune or epileptic abnormalities in autism (Hirsch, Engel-Levy, DuBois, & Hardesty, 1990; Stefanatos, Grover & Geller, 1995).

Another aspect studied which may contribute to autism is blood flow in varying regions of the brain. Cerebral blood flow (CBF) was recorded in a study of 23 children diagnosed with autism (ages 2-13) and 26 non-autistic mentally retarded children (ages 3-12). Data showed decreases in CBF of autistic children in the bilateral insula, superior temporal gyri, and left prefrontal cortices. The obsessive desire for sameness in the environment, often observed in autistic individuals, is associated with altered perfusion in the right medial temporal lobe (Ohnishi et al., 2000).

There is some evidence for the effects of serotonin (5-HT) in autism (Cook et al., 1997). For example, in a study comparing 20 autistic children and adolescents (ages 3-17) to 20 typically developing children, it was found that the autistic children showed a significantly higher density of (sup-3H) Par binding sites than in the typically developing children. These findings suggest that the 5-HT transporter may have a specific role in the disorder of autism (Marazziti et al., 2000).

The study of high GABA levels has also been explored as a possible cause of autism. In a recent study, a blood and urine analysis of a 8-year old male with autism showed high levels of GABA (Cohen, 2000). GABA is a major inhibitory neurotransmitter in the corpus collosum, and extremely high levels are thought to lead to abnormal development of the axons in the corpus collosum. The results of abnormal development in the corpus collosum could explain autistic behaviors such as self-stimulatory actions and language delays (Cohen, 2000).

How is Autism Treated?

The treatment of autism in the 1950's and the 1960's evolved from psychodynamic theory, most noted in the work of Bettelheim (1967). The recommendations for treatment aimed at "breaking through the shell of autism." Once the hope of "emotional recovery" faded, the research of the 1970's shifted to seeing autism as a cognitive and linguistic impairment (Rutter & Schopler, 1987; Wing, 1976), opening the door to behavioral intervention (Lovaas, 1987) and related models of structured teaching.

There seem to be as many interventions for children with autism as there are diagnoses in the United States. Interventions can be through the use of medicines, foods,

or therapy techniques. Less commonly used methods are various “special diets,” vitamins B6 and magnesium, and secretin use. More common interventions which are able to be measured empirically through use of applied behavior analysis are speech and language pathology, occupational therapy, physical therapy, social skills education, discrete trial, and sensory integration techniques (Koegel & Koegel, 1995). Although there isn’t a single method of intervention that has been found to be effective for all children with autism, there are a few approaches commonly used to aid in teaching language acquisition and expression (Howlin, 1998). There is also consensus that early intensive treatment that involves parents and includes direct teaching of essential skills, with an opportunity for planned integration, can produce remarkable changes in the child (Jordan & Jones, 1999). Recent reviews of research on early intervention programs suggest 20-40 hours per week of intensive programming for the child with autism (Dawson & Osterling, 1997; Harris & Handleman, 1994).

The six most widely known interventions used are:

The TEACCH Method (The Treatment and Education of Autistic and Related Communication Handicapped Children approach) is designed around some core autistic traits such as preference for sameness and routine, visual learning, and independence. It focuses on supporting functional behavior in daily routines through the use of visual and environmental cues (Lovaas, 1981).

The Greenspan Method focuses on developing emotions by mobilizing affect through therapeutic and pleasurable interactions. This method involves using a technique called “floor time,” which involves one-to-one interactions between child and parent in an effort to assist the child in learning a wider range of

emotional affect. In turn this facilitates better problem solving and cognition (Greenspan, 1992).

The Miller Method respects the rituals and behaviors used by autistic children to understand their world, and expands these rituals into meaningful actions. The primary goal of this method is to develop the variety and flexibility of social, play, and daily routines. Intervention begins with sensorimotor activities in an interactive context to help children improve awareness not only of themselves, but others around them (Miller & Miller, 1993).

PECS (Picture Exchange Communication System) uses pictures and symbols of common activities and items to assist the child in communicating his or her needs. The child first learns to order the pictures to form sentences, and later learns to express verbally what he or she wants without the pictures (Schwartz, Garfinkle & Bower, 1998).

Facilitated Communication refers to the therapist or teacher working “hand over hand” with the child helping him or her to use a keyboard to type various letters, words, and phrases. The teacher “facilitates” the communication by pushing on the top of the fingers of the autistic child to create words and sentences. It is the hope of the teacher that these words being facilitated will be learned and recognized (Konstantareas & Gravelle, 1998).

Discrete Trial Training is a basic tool to enhance learning and is based on the child’s individual motivation to respond. Most typically used in classroom settings, it involves one-on-one intensive drills for learning such things as colors, shapes, and items in the environment (Myles & Simpson, 1990).

Research on the Impact on Families

From reading about the characteristics of an autistic child, as well as understanding that while there is no cure, there is hope for improvement through some of the various treatments reviewed above, there should be little doubt that autism will have a major impact on any family. Research on autism and the family has focused primarily in three areas: diagnosis, services, and families coping ability.

There is some research evidence indicating that the way in which diagnostic information is conveyed can have long-term influence on parental attitudes, on families' level of stress and acceptance, and on coping strategies. Delays in obtaining a diagnosis are a particular source of distress for parents (Quine & Pahl, 1987). Although there have been indications of improvement in diagnosis and intervention (Pfeiffer & Nelson, 1992), parental accounts of their experience continue to indicate dissatisfaction. For example, Smith, Chung, & Vostanis (1994) explored the problems faced by 127 parents of children with autism. Although they found significant improvements in the age at which diagnosis was made, their study also documents the continuing frustration of many parents in their attempts to obtain diagnosis, support and appropriate services.

Another study surveyed 1,295 families seeking a referral and diagnosis for their child with autism (Howlin & Moore, 1997). In the majority of cases, parents had serious concerns about their child's development at a very early age, with almost half recognizing that there were problems before the child was 2. The main areas of concern centered around abnormalities or delays in language or social development but very few families (less than 10%) obtained any form of diagnosis when they first went to seek

advice. As was also found in the Smith et al. study (1994), many parents were referred to another professional after this initial consultation, but over one-third were told either not to worry, or to return if the problems persisted. Most families went on to seek further assessment; over half did not receive a diagnosis of autism until the child was 6 years of age. Not surprising, many families' views of the diagnostic process were far from complimentary.

A more in-depth look at the experience of parents in the diagnosis of autism was conducted by Midence and O'Neill (1999). They interviewed four families about their experience with recognition and eventual diagnosis of autism. All of the families were aware of early abnormalities in their child's development and this is consistent with previous research (Smith et al., 1994; Howlin & Moore, 1997). The feeling that "something was not right" led parents to search for an explanation for their child's behavior, but if the diagnosis was incorrect then confusion, despair, blame and guilt resulted. Confusion over diagnosis also resulted in family difficulties to the extent of being isolated by other relatives and friends. Difficulties in marital relationships were not uncommon, and mothers often blamed themselves for their child's autism. Several parents reported having doubts about the diagnosis they were given initially, and in one case, a parent was blamed by her doctor for her child's behavioral problems. The comments of the parents highlight the need for early diagnosis and better awareness of development problems in young children among health professionals. This is consistent with earlier findings by Piper and Howlin (1992) indicating that the earlier the age at which diagnosis is made, the greater the degree of parental satisfaction. Parents in this study felt that once they knew what was wrong with their child, and a label or diagnosis

was given, they were able to understand their child's behavior, accept the condition, and plan for the future.

Several studies have examined the interaction of parents with their service providers. In a study by Gray (1993), 35 parents of children with autism involved in a treatment program were interviewed, along with the staff of the treatment center. Parents were asked about their recognition of their child's symptoms, their feelings about the diagnosis, and their dealings with treatment center staff. Interviews with staff focused on problems presented by the families and how the staff dealt with them. Gray (1993) found that perceptions by parents differed in several ways from the staff. For example, while the staff believed that the behavior of children with autism could usually be significantly improved, they did not believe that a complete recovery was possible. On the other hand, parents expected their children with autism to have a near normal life. In another example of differences between staff and parents perceptions, the staff's view of children with autism was that these children do not feel normal affection for other people. However, most parents interviewed felt that their child showed affection, and that this belief was an important motivation for the parents to have hope and continue to seek services.

Kohler (1999) conducted phone interviews with 25 families to examine the services received by young children with autism and their families. Results revealed that most families interact with many different agencies in order to receive the necessary services. On average, these families received 6 different services from 4 or more agencies (involving 7 or more professionals) and nearly 37 hours of intervention a week. Some services focused on the child with autism (school placement, therapeutic support staff, speech or occupational therapy), and other services were designed to benefit other family

members (case manager, parent information sessions, respite care, sibling support classes). Several problems were also identified, as some families had difficulty accessing services, had limited involvement in interventions, and reported that providers engaged in little interagency collaboration. These results highlight the incredible demands placed on a family with a child with autism, and highlight the strain and stress experienced by such families.

Dumas, Wolf, Fisman, & Culligan (1991) also found that families with children with autism have higher levels of stress when compared to families with children with Down's Syndrome, behavior disorders, and children with normal development. Findings for the thirty families who had a child with autism revealed that mothers of children with autism perceived themselves as experiencing significantly more stress in their parenting tasks than did other mothers in the study. Similar findings were reported by Gray (1994), who found that parents of children with autism experience high levels of emotional stress, anxiety, fear and guilt. Through interviews with 35 parents of children with autism, Gray (1994) also confirmed other's findings (Smith et al., 1994; Howlin & Moore, 1997) that parents of children with autism are usually the first to recognize the symptoms, and, subsequently, have difficulty in convincing reluctant grandparents and medical personnel of the problem. Gray, too, reports that for many parents, the diagnosis of autism brought feelings of relief. Gray's study focused primarily on the coping strategies of these parents. The evidence from this study indicated no one coping strategy was inherently more successful than any other. Irrespective of whether the strategy was to rely on the support of family members, or on religion, or on one's individual qualities, to withdraw socially, or to make use of treatment services, it seemed to have little effect on how well

parents coped with their child's autism for the outcome was the same – all the parents believed they were successful in coping with their child's disorder and that they lead lives that were rewarding and valuable.

Such coping strategies were also discussed in a report by Schall (2000), who conducted in-depth interviews with three families with a child with autism (all boys). All three families described the period between the time when they first noticed that something was different to the time when they received the diagnosis as a time of great stress. As found in previous studies, all of the families discussed an overwhelming number of visits to doctors, psychologists, hospitals and therapists to try to understand their child's problem. When the families finally received a diagnosis of autism, their reactions were described as both horrible and empowering. The families described numerous strategies they had for coping with many difficult situations. All of the families shared stories of varying levels of rejection by family, friends, and strangers in the community. Perhaps the most surprising finding was that, in spite of intense and extreme stress, all of the parents talked with great fondness about their children and how they were able to hold onto hope for their child diagnosed with autism.

Purpose of this Study and Research Questions

The purpose of this study was to examine the impact of having a child with autism on the family. Few studies have examined how families cope with it. Autism is an extremely disabling disorder that places severe strains on the families of children with autism. Problems with language and destructive behavior - just to name a few - represent serious coping challenges to the most capable of families. Although many children diagnosed with autism improve with treatment, few ever lead anything approaching a normal life. In fact, many are severely impaired for their entire lives, and their families have to provide care for them for many years. Consequently, understanding how families deal with this issue is an important issue.

This study focused on three main questions:

1. When was autism first recognized and diagnosed?
2. What is the nature of intervention services received by families of children with autism?
3. What has been the impact on the family of having a child diagnosed with autism?

Chapter 3

METHODOLOGY

Sample

The study was comprised of a non-random sample of 21 families with children who have been diagnosed with autism. The parent who is the primary caregiver of these children was invited to be interviewed about recognition/diagnosis of autism in their child, services accessed, and the impact of having a child with autism on their family. The convenience sampling method was employed due to the limited number of families with children with autism, as well as the sensitive nature of the study. The sample was acquired through a letter mailed directly to families by the Autism Society of Maine. (Appendix A). Five hundred letters were mailed. Twenty-three parents contacted the Autism Society to be express interest in being interviewed; twenty-one parents (19 mothers; 2 fathers) were eventually interviewed. Two other families were unable to find a good time to participate in the interview. The children with autism (17 males; 4 females) in these families ranged in age from 3 to 26 years at the time of the interview. This sample's ratio of males to females with autism (4:1) corresponds with the national ratio which has found that autism is found four times as often in boys than in girls (Centers for Disease Control and Prevention, November 16, 2001).

Procedure

The researcher conducted one-hour phone interviews with parents of the children. The interview consisted of fifteen open-ended questions, which were approved through the Human Subjects Committee of the University of Maine (Appendix B). Prior to the start of the interview, subjects were reminded that any and all responses would be kept

strictly confidential, and upon completion of the interview their responses would be labeled with a case number (e.g., Case #1, Case #2, etc). Questions were asked to each participant in the same manner and were restated as needed.

Interview Questions

The interview was structured around the three areas of interest: recognition and diagnosis of autism, services accessed, and the impact on the family. As outlined in Appendix B, there were four questions focusing on recognition and diagnosis, five questions investigating services utilized, and six questions focusing on the family and how they have dealt with having a child with autism.

Data Analysis

This was an exploratory study and was completed using a relatively small number of people. Therefore, the major portion of the data analysis was done through descriptive statistics. Responses were analyzed for commonalities and differences and results are reported in the next section.

Chapter 4

RESULTS

This study examined the impact of having a child with autism on the family.

Below are the research findings for the three major areas of interest focusing on recognition and diagnosis, intervention services, and impact on the family.

Recognition and Diagnosis

One of the major research questions was, **“When was autism first recognized and diagnosed?”** To answer this question, parents were asked four specific questions. The first question was, “How did you first learn that your child had autism and how old was the child?” Most parents described how they were referred by their pediatrician to a specialist for an evaluation. Most parents (15 out of 21) said that a psychologist diagnosed their child with autism, while the others received a diagnosis by a neurologist (n=3) or neuropsychologist (n=3). While their age at diagnosis ranged from 18 months to 12 years of age, most of the children with autism (13 out of 21) were diagnosed during the preschool years.

“I noticed at 2-3 months of age that my child did not have good eye contact, was sensitive to certain sounds and movement and did not interact with others. Our family practitioner noticed something was different. We eventually went to Children’s Hospital in Boston where they confirmed that something was wrong and made a referral to a psychologist back in Maine. At age four and a half our child was finally diagnosed with autism by this psychologist.”

“When my child was 18 months old I talked with my pediatrician about signs of autism. The pediatrician suspected autism and sent me to a clinic for an evaluation and then eventually to a neurologist who diagnosed my son.”

Parents were also asked, “When did you notice something was different or not quite right with your child?” All of the parents recognized that something was different in their child by age four. The average age of the child when the parent first recognized

something was wrong was 15 months. In fact, three parents said that they felt something was wrong the day the child was born. Parents described observing behaviors that are typical signs of autism, including: lack of eye contact, rigidity when touched, self-stimulatory behaviors such as hand flapping, toe-walking, sensitivity to certain noises, lack of social interaction, repetitive play, need for schedule, language delays, as well as loss of language.

From the time they recognized that something was different to the time they actually received a diagnosis of autism ranged from six months later to ten and a half years later. However, most parents (13 out of 21) did receive the diagnosis within three years time. In the eight cases where the diagnosis was made much later, it was due to the parent initially being told by their doctor that nothing was wrong, or the parent was given an incorrect diagnosis (i.e., PDD, OCD, ODD, and ADHD) and only later identified as having autism. For example,

“I went to the doctor when my son was two because he did not talk – I knew something was wrong but I was told to wait – that he will be fine. I took him to Child Development Services when he was two and a half and I had to wait five months before seeing a psychologist – who eventually diagnosed him with autism.” (received diagnosis within 3 years time)

“When I went to my doctor and told him something was wrong, he said that sometimes boys are slower than girls.” (doctor initially said nothing wrong)

“I noticed something was wrong on the first day - he would not latch on during breast feeding. Later I noticed he was in his own world. When he was four, I took him to a psychologist who diagnosed him with OCD and ODD. Later a friend sent me a book on autism. I took him to a different doctor when my son was ten years old who diagnosed him with autism.” (parent given incorrect diagnosis)

When asked, “Did you accept the diagnosis of autism or did you disagree/challenge/seek other diagnosis?” most parents (20 out of 21) said they accepted the diagnosis. Only one parent doubted the initial diagnosis and sought a second opinion.

“I didn’t challenge the diagnosis because everything fit into place. After reading about autism, I said ‘this is so much like her.’” (acceptance)

“Yes, I accepted the diagnosis. I knew it was autism by that time, since I had been doing a lot of my own research.” (acceptance)

“I accepted the psychologist’s diagnosis. We had figured it out.” (acceptance)

Finally, parents were invited to talk about their reaction: “Please tell me about your reaction(s) when you first learned of your child’s diagnosis.” Parents often mentioned several emotions. The most common response was relief (11 out of 21 parents), followed by grief and loss (mentioned by 9 parents), shock/surprise (6 parents), and self-blaming (mentioned by 2 parents). Examples of responses included:

“I was so thankful. I finally had something that made sense. Other labels did not make sense.” (relief)

“When the doctor told me, I had the same feeling as when my grandmother died.” (grief)

“This wasn’t supposed to happen to us. I thought this was something he would grow out of.” (shock)

“I cried when I left the office. I felt that it was my fault, since I had been exposed to shingles early in the pregnancy.” (self-blame)

Intervention Services

The second major research question asked, **“What is the nature of services received by families of children with autism?”** Five questions were included in the interview to obtain this information. The first question asked parents, “What services were put in place to help you? And were these difficult to obtain? If so, please explain.” Nineteen of the 21 parents said they had been assigned a case manager to coordinate services for their child. The most common services were speech therapy (n=17), occupational therapy (n=17), in-home behavior specialist support (n=7), developmental

therapy (n=8), applied behavior analysis (n=5), physical therapy (n=5), respite (n=4), and one-on-one classroom support (n=2). Other services mentioned by individual parents included counseling, music therapy, play therapy, neuro-feedback therapy, social skills training, and life-skills training, and group home placement for child.

In terms of experiencing any difficulties in obtaining these services, ten parents said they had no difficulty in obtaining services once their child was diagnosed with autism. However, seven parents said that they were placed on a waiting list, two parents experienced difficulty in obtaining services within the child's school, and two other parents found it difficult to obtain services within their area.

"The services were really easy to obtain – my case manager put everything together for us right away."

"My child was put on a waiting list for being assigned to a case manager. I was told that in the meantime, I should do the case management and coordination of services – which was appalling since I was already so stressed."

"It wasn't that the school felt he didn't need services, but that the school had limited resources."

Parents were asked, "How have you been treated with regard to your opinions and knowledge of your child's needs by professionals (doctors, therapists, etc.)?" Half of the parents (n=11) felt they had always been treated with respect, whereas the other half of the parents interviewed (n=10) had experienced some disrespectful interactions with professionals.

"I was treated with respect – in fact, one doctor said I knew more than he did!"

"One doctor told me, 'Your son has autism and there is nothing you can do about it so just live with it.' Yet I knew that wasn't the case."

"The psychologist treated me like it was my fault. He said my child's behavior was because of his home environment."

The next question asked of parents was, “What is the families involvement in the services?” Most parents identified the mother (n=13) as the primary person who coordinated the services their child needed. Seven people said both parents were involved, and only one said that the father took primary responsibility for services. This included transporting the child to and from meetings, as well as coordination of and attendance at meetings. Most parents also talked about the enormous amount of paperwork involved with obtaining and receiving the services.

“There is a lot of travel involved. I travel over one hundred miles a week just for therapies. I also have overwhelming amounts of paperwork – I have to keep my own file just to stay organized.”

“There is so much paperwork. We sometimes avoided doing the paperwork so that someone else would do it for us.”

“I attend all the meetings for my son. There has been just an enormous amount of paperwork and hours and hours of therapy each week – not to mention a lot of travel involved which is stressful on our family because it disrupts home schedules and meal times. Our time and our home is not our own because we are always going to meetings or having people in our home.”

The fourth question asked parents, “How do you feel about the services? Are there any problems with the services you are receiving and if so, please explain.” Eight of the parents felt that the services were good and they did not have any problems. However, the other 13 parents did describe some problems they were experiencing. Most typically, the parents talked about not being able to find a well-trained person to provide the services (n=7), not having enough hours of the needed services (n=4), and the issue of distance – in that in order to obtain the needed services, they were required to travel great distances (n=2). For example,

“Although we had the services we knew our child needed, we were not able to obtain the number of hours we felt our child needed each week to develop.”

"We were assigned an occupational therapist – which was great. But she did not know anything about sensory integration – which our child had a need for. We also had no support group in our area."

"I am trying to get closer services – which has been a dead end street. I currently travel 37 miles each way just for ABA services."

Finally, the parents were asked, "What services have been most effective/helpful to your child's development? What impact have the services had with regard to your stress/coping?" The most effective/helpful services mentioned by parents included speech therapy (n=9), having a behavioral specialist working with the child at home (n=7), occupational therapy (n=6), applied behavior analysis (n=2), and physical therapy (n=2). Individual parents also listed respite, play therapy, social skills training, life skills training, having the one-on-one classroom aide, and being able to place their child in a group home. In terms of stress/coping, most parents (n=15) said that the services they received greatly reduced their stress. However, six parents stated that their stress level actually increased as a result of the services (due to such things as paperwork, travel, meetings, dealing with providers). Examples from parents included:

"The number one service would have to be speech therapy. It wasn't so much the speech, but the knowledge and experience that the speech therapist had in the area of autism. She assured us that our child would improve and that she had seen other similar children improve." (reduced stress)

"Respite services have been a godsend in terms of our stress and coping." (reduced stress)

"Services have increased my stress level because of all the paperwork, signing releases, doctor visits, therapy, respite care paperwork and meetings, plus not knowing if Medicaid will pay for services or not." (increased stress)

"While I appreciate the services we receive, it is stressful having the worker always looking to the parent for the next thing to do and how to handle our child." (increased stress)

“While some services helped, but it has been very stressful – especially when the behavior specialist is not knowledgeable in the area of autism or is not consistent in working with the child.” (increased stress)

Impact on the Family

The final major research question was, **“What has been the impact on the family of having a child diagnosed with autism?”** To answer this question, parents were asked six specific questions. The first question was, “What has it been like to parent this child?” While two of the parents said it was no different than parenting any other child, several parents talked about what a positive experience it has been to be the parent of a child with autism (n=5). However, the overwhelming majority of parents (n=17) used the word “stressful” to describe their experience. For example,

“It has been an honor to be given a child like this – to parent a child like this” (positive)

“Even though God never asked me if I could handle this, my son was given to me so that I may teach others – he has brought me out of my quiet shy self.” (positive)

“He has been a joy and a sweetheart. I wouldn’t change anything.” (positive)

“It has been stressful, aggravating, agitating and overwhelming at times – it is hard to get others to understand him.” (stressful)

“It was stressful – because of behavior problems and because of how outside people dealt with him. When my child was little, a neighbor next door told other parents not to let their children play with him because he was weird.” (stressful)

“It was heartbreaking, stressful, and devastating – especially for my husband. We were quite overwhelmed with demands and needs of our child.” (stressful)

“Some days it is a living hell – 30% of the time you feel like you are in a normal family, and 70% of the time you are juggling so many things you don’t know where you are going.” (stressful).

When asked, “How has the family dealt with this diagnosis?” many of the parents (n=11) talked about the need to adapt their schedules and the need to have structure

within the home. Some parents described how they read and learned more (n=5) in order to deal with the diagnosis. Other parents made sure their child got the services they needed (n=3), and two parents discussed joining a support group to help them deal with the diagnosis. Examples of parents responses include:

"We have to make modifications in our plans because certain noises and sounds bother our son." (need for schedule/structure)

"My husband and I had to set up a daily schedule for our life – especially when our child was younger. We were not able to leave together very often." (need for schedule/structure)

"There is a lot of daily planning that a lot of other families take for granted." (need for schedule/structure)

"Our daily life is a routine – if you throw anything different and unpredictable in out son melts down – which effects the whole family." (need for schedule/structure)

"As we read and learned more information as our child got older, it became much easier to deal with the diagnosis." (read/learned more)

"I am involved in a support group right now. The more I am associating with other parents, the better I feel." (support group)

The parents were also asked, "In what ways has this impacted the family? (e.g., stress, coping, daily life, vacations, free time away from child)." Two parents said that having a child with autism had no impact on the family. However, most parents offered multiple answers to this question. The most common response was that there was little or no time for fun/vacations (n=10), followed by the need to plan ahead (n=8), and the stress this placed on the marriage (n=7). Other ways that having a child with autism impacted a family included having little or no free time for self (n=3), child not being able to have friends (n=3), the impact on mom's career (n=2), and safety concerns (n=2).

"We took only one vacation in 19 years. I was at the end of my rope when my mother took the child while I went to Disney World." (no time for fun/vacation)

"We have gone on only a few trips – our last vacation was 4 years ago." (no time for fun/vacation)

"We have not taken a vacation as a family since the diagnosis." (no time for fun/vacation)

"We have to plan everything ahead, from going to the grocery store to shopping because our son can perseverate on certain things which makes trips very difficult." (need to plan ahead)

"I am always aware of things in the environment that may set my son off – which takes a lot of planning and thinking ahead before I go anywhere with him. We can never just pick up and leave." (need to plan ahead)

"My husband complained last night that we have not had an overnight alone since our daughter was born – she is now six years old." (stress on marriage)

"It cost me my marriage. We were divorced when my child as three." (stress on marriage)

"It's hard to get a minute alone – to just take a break from everything." (no free time for self)

"He (my son) never gets invited anywhere and doesn't have friends over to the house." (child's friendships)

"I had a career before my child's diagnosis. Now all that doesn't seem important anymore. I work a part-time job so I can be home with my son." (impact on mother's career)

"We have to use motion detectors on the doors and windows and make sure there aren't sharp objects laying around that our son may play with." (safety concerns)

The next question focused on siblings: "How has this impacted your other children, and your interaction with these other children? What have you done to try to respond to sibling's needs?" Five of the children with autism had no siblings. For the other sixteen families, most of the parents (n=12) described how the sibling experienced resentment and/or jealousy toward the brother or sister with autism. Parents also talked about siblings feeling sad (n=2), afraid (n=2), and awkward (n=1). Only two parents said the child's sibling was accepting.

"My daughter will say that I love my son (with autism) more than her and that I spend more time with him." (resentment/jealousy)

"His sister gets very angry and jealous at times at all the special needs her brother has and the amount of time spent on him." (resentment/jealousy)

"Deep down my daughter resented all the attention her sister with autism received." (resentment/jealousy)

"Our son has a hard time and often feels hurt. He has told us that he feels sad because he thinks we love his brother more than him which hurts us." (sad)

"My other child has a diagnosis of anxiety disorder which may be due to his high level of alertness and fear of being hurt by his brother with autism." (afraid)

"My other two children are very understanding and have a lot of questions about autism. They have even started learning sign language so they can communicate with him." (accepting)

Most parents tried to help the sibling deal with the situation by talking about/educating the sibling about autism (n=5), spending extra time alone with the child (n=5), involving the sibling in the therapy (n=2), making sure to involve the whole family in activities (n=1), and separating the children when there was fear of being hurt (n=1).

"When our daughter gets angry about our son's special needs and the time we spend with him, I will often read books to her and discuss the diagnosis." (talking about/educating sibling)

"When our child with autism was born, his sister was just turning two. We had the PEC System done at home which the sister learned also – they are inseparable." (involving sibling in therapy)

"We are very in-tune with our daughters jealousy at the attention her brother gets. Her dad will take a day off from work to try to do everything on the daughter's list she would like to do. We also have our daughter sometimes stay up later than our son so that we can spend time and talk." (parent spending time alone with sibling who does not have autism)

Parents were also asked to talk about the role of grandparents. Specifically, the interview include the questions: "How have they dealt with this child? How are they involved in the care of the child or as a support for you?" Between the 21 families

involved in this study, there were 72 grandparents. Approximately 60% (n=45) of the grandparents were described by the parent as being accepting of their grandchild's diagnosis, while about 40% (n=27) were not accepting. Of those 45 grandparents who were accepting, most lived so far away that it was not possible to be actively involved with their grandchild. Only seven grandparents were actively involved in the care and support of the child; of these seven grandparents, five of them were the maternal grandmother. It was also found that of those 27 grandparents who were not accepting, it was most likely to be the grandfather on either side of the family (19 grandfather versus 8 grandmothers).

"My parents – especially my mom is supportive. Both of them have taken the time to learn more about the diagnosis which I think has helped in their acceptance of it." (accepting)

"My mother has been supportive since day one and is still an important source of support." (accepting)

"My parents (maternal grandparents) adore him. He stays with them every third weekend and always looks forward to seeing them." (accepting)

"My parents are very supportive – they treat him like a regular kid." (accepting)

"My in-laws have spent three hours with him since he was born – he is now four years old. They think we should have another child so they can have a normal grandchild." (not accepting)

"I don't tell my parents much of what is going on. They are from the old school and just don't understand." (not accepting)

"My husband's parents are still in denial. They keep telling us that he will just grow out of it." (not accepting)

The last question asked about other relatives/family members: "How have other family members dealt with your child's diagnosis? What role have they played?" All of the parents focused on their own siblings. Most (n=19) of the parents interviewed said

they had brothers and/or sisters who were accepting and supportive of their child with autism. However, due to distance, most of these aunts and uncles were not actively involved in the care of their niece or nephew due to distance. Only three parents had a sibling (2 sisters; 1 brother) who was actively involved with their child.

"My sister is emotionally supportive, but not very involved because she lives several states away." (accepting and supportive)

"My sister is less than one mile away and helps with childcare. She is such a source of support." (accepting and supportive)

"My family has been supportive. My husband's brothers and sisters are supportive and accepting of him but live quite some distance away." (accepting and supportive)

"I have one brother and two sisters who have been supportive of me and my son since day one." (accepting and supportive)

"I have one brother who loves my son and is great with him but lives in another country, so he does not see him much." (accepting and supportive)

"My sister is the love of his life – he goes over there all the time." (accepting and supportive).

Chapter 5

DISCUSSION

This study provided some insight into the lives of 21 families who had a child with autism. The interview explored three major areas of interest: recognition and diagnosis, intervention services, and the impact of having a child with autism on the family. The results will be discussed below and implications for those who work in the area of autism. Limitations of this study will also be noted.

Recognition and Diagnosis

Parents in this study knew very early on that something is wrong with their child. Some parents said they even knew something was different with their child the day of birth. These findings are similar to reports by parents in previous studies in which almost half of the parents interviewed recognizing problems before the child was two years of age (Howlin & Moore, 1997; Smith et al., 1994).

From the interviews with these parents, it appears that the system seems to be set up in such a way that leads to months of waiting, numerous referrals, and in some cases, very late and inaccurate diagnoses. This has implications for the health care system and specifically for pediatricians who often are the main source of referrals for children who are suspected of having autism.

Often parents "instincts" can be over-looked or discredited, only later to become true, leading to delayed diagnoses. Several parents in the study said they were told either nothing was wrong, or were given an incorrect diagnosis. In a study by Smith et al. (1994), over one-third of the parents surveyed were told either not to worry, or to return if

the problems persisted which seems similar to the attitudes among several doctors that the parents of this study encountered.

Most parents said that they accepted the diagnosis of autism when it was finally confirmed. More than half of the parents interviewed felt relieved and almost as many felt feelings of despair, sadness, and even devastation. Although the diagnosis of autism can seem so tragic and overwhelming at first to a parent, there was, in many cases, a drive to move forward and do what needed to be done to help the child improve. Parent's relief seemed to be strongly associated with now having an answer, a diagnosis to work with, which was also found in a study by Piper and Howlin (1992). Their study showed how once the parent(s) knew what was wrong with their child, and had a diagnosis, they could better understand behavior, and plan for the future.

Looking at the feelings expressed by parents in the study, it can be seen how important it is to have an early diagnosis and how this helps to give a "starting ground" and bring relief. This has important implications for pediatricians, psychologists, and neurologists, who give the diagnosis to the family. In many cases, the parents are feeling sad, frustrated, and devastated with nowhere to turn. Counseling services or referrals for these services might be very effective in helping to meet the emotional needs of parents while they cope with numerous feelings and wait for services to be implemented.

Intervention Services

After receiving the diagnosis, most families were given a case manager who helped them set-up intervention services that would help both the child and the parents. Even though speech and language therapy and occupational therapy were the most often used services reported, many families also used various other services to help the child

develop and integrate into the community. In a study by Kohler (1999), it was found that families generally used several services to help benefit both child and family. In terms of difficulties experienced in obtaining services, more than a third reported being placed on a waiting list, and several others either finding it hard to obtain services in school or not being able to obtain any services in the community. Kohler (1999) also found that parents identified such difficulties in accessing services.

It can be seen that obtaining services is more than just a simple referral. Parents are often frustrated with long waiting lists and in some cases no services at all. More than half of the parents interviewed described that they were having problems with services, most typically not being able to find a well-trained person or not receiving enough hours of service each week. In a state with so many rural locations, it is important to have incentives for increased numbers of service providers to enter these rural locations and even work in the urban areas where the providers are stretched thin. Networking, advertising, and increasing budgets to meet the needs of these children is clearly needed.

Nearly half of the parents surveyed felt that they were not respected by professionals such as doctors and therapists. When doctors and other professionals do not respect the opinions/concerns of parents, there can be very negative consequences. A late diagnosis, or wrong diagnosis can result from a doctor who may have overlooked the most important source of information about the child, the parent.

Being a parent of a child with autism places many demands, some of which are frequent driving to and from appointments, paperwork, and meetings with service providers. In a study by Kohler (1999), it was found that incredible demands were placed on a family with a child who had autism, and the stress associated with these demands. It

was found in this study that parents did much of the transporting, paperwork and filing, and attendance at meetings for their child. Most parents discussed the tremendous amount of paperwork involved in receiving services, as was also found in a study by Schall (2000) who noted that families discussed an overwhelming number of visits to doctors, psychologists, hospitals, and therapies. Finding ways to streamline paperwork and provide transportation for families and children could help ease one or more of the many stresses a parent encounters on a daily basis.

The most helpful therapy was found to be speech therapy which was also combined with several other therapies. More than two-thirds of the parents interviewed felt that the services they received for their child greatly reduced their stress. It was interesting to note, however, that almost a third of the parents found services actually caused more stress by adding time spent on paperwork and people in and out of their homes on a regular basis.

There are several implications of the findings on intervention services received by families. There seems to be a need for increased training of the therapists, behavioral specialists, and others that serve families. Another contributing factor to dissatisfaction was that there are not enough available hours that a provider is able to give to the parents child. Several parents felt that they had the right types of services, but that the intensity of the interventions were lacking and many more hours were needed. The feelings expressed by parents clearly show areas that need improving upon such as comprehensive and ongoing training for professionals and increased state funding for children to receive the recommended amount of therapy hours.

Impact on the Family

Most parents interviewed, expressed that the experience of being a parent to a child with autism was stressful. Some parents also talked about the experience as being positive. Similar findings were reported in a study by Gray (1994) in which it was found that parents of children with autism experienced higher levels of emotional stress, along with other feelings.

More than half of the parents talked about the need to adapt their family's schedules and have structure in the home. Other ways of dealing with the diagnosis included finding services for their child, and reading and learning more. Only a few parents identified a support group as a source of support, with other parents saying that there wasn't an available support group in their area. It seems that there could be many more support groups for parents throughout Maine to help parents not only network and connect with peers, but access the available information that will help them and their families cope and move forward.

The impact of having a child with autism on the family is tremendous, from having to plan ahead for simple trips, to not having free time alone to just relax. Nearly half of all families said that the diagnosis impacted the family by making vacations/fun virtually impossible. Many others reported stress placed on the marriage. Dumas et al., (1991) found stress to be higher among parents of children with autism than parents of a child without autism. Gray (1994) also discussed in a study of 35 parents, the high levels of emotional stress experienced by parents, and the anxiety and fear that can result.

It is interesting that some families talked about the impact as relating to safety concerns and a fear of children hurting themselves or others. It can be seen that not only

is the diagnosis of autism stressful on a family, but that the impact on the family is far reaching, including the many stress factors of having to plan for even the smallest trip to the store, to difficulties in getting a free minute alone.

A way to give some stress/emotional relief to parents is to have increased funding for respite so that a parent(s) can get away and more trained people that can provide quality respite services. Less than 20% of parents interviewed in this study reported using respite, many being on waiting list and others not having access to trained professionals in their area. None of the parents interviewed talked about counseling for themselves. It seems that there are many sources of stress that parents live with on a day-to-day basis that are often over-looked and not addressed.

Siblings are often affected in several ways by having a brother or sister with autism. Most parents reported that the sibling of their child with autism experienced jealousy and/or resentment due to attention and services that their brother/sister were receiving. Other feelings included sadness, fear, and acceptance. Very few siblings were accepting. Most parents responded by talking to and educating their child about their sibling with autism. Parents also made special days for the sibling or involved the sibling whenever possible in activities with their brother/sister with autism.

The findings have implications for further study of siblings emotional needs and possible interventions. It seems that an increased number of sibling support groups and peer groups for siblings of a child with autism could help to explore feelings of sadness/jealousy and help these children connect with peers who are going through similar experiences.

Relatives can be an important source of support, but can also not be accepting and lead to the family of a child with autism feeling rejected. Schall (2000) found in a study of three families with children with autism, that all families shared stories of certain levels of rejection by family, friends, and strangers in the community. In this study, almost half of all grandparents were not accepting/understanding of the diagnosis with grandfathers being more than twice as likely as grandmothers to not accept the diagnosis. The maternal grandmother was the most actively involved grandparent in childcare and support. It can be seen that there needs to be more education directed at grandparents, especially grandfathers on the diagnosis. Several parents said that reading and talking about the diagnosis helped their grandparents slowly come to understand and accept their child.

Most parents reported having brothers and/or sisters accepting and supportive of their child. With aunts and uncles, distance was the main contributing factor to them not having an active role in care of the child with autism. Less than 20% of aunts and uncles took an active role in child care.

There are several implications of the findings on family involvement. While there were more grandparents actively involved in childcare for the child with autism, there were fewer grandparents than aunts and uncles that were accepting of the diagnosis. Grandparents, if educated more on autism, could be a very strong source of emotional support as are many aunts and uncles of the child. The community as a whole should look at the various ways in which to not only educate the family of a child with autism, but focus on the grandparents, who are part of the family unit and can be an invaluable source of support.

Limitations of this Study

There are several limitations to this study. The sample consisted of only 21 parents interviewed from a rural New England state. We do not know anything about the parents who chose not to be interviewed – this may be due to time constraints, other pressures, extreme stress, and negative experiences. Those who responded may be much more comfortable with their situation in terms of proper and early diagnosis, level or services, and treatment by professionals. The sample obtained may have consisted largely of very comfortable parents receiving appropriate services and not of those families who have the stories of inadequate resources and poor services.

The other parent in the family was not interviewed about their perspective which may have differed greatly. Two people can give very different answers to the same situation or experience.

Recall may have been difficult – some of the interview questions asked the parent to reflect back on experiences and feelings from many years ago which can greatly affect recall of information. This could lead to inaccurate answers to some of the interview questions.

Since the study was done with volunteer interviewees, they were not familiar with the interviewer and may have been less likely to share difficult feelings and personal information, than with someone they knew. This may have limited the scope and range of information collected.

Conclusion

Families who have a child with autism share many of the same feels of frustration, stress, constant need for schedules, and also feelings of hope and goals for the

future. Parents often realize early on that their children are different but they are not sure just what is wrong. When a referral is finally made it is often the parents who are feeling desperate, traumatized and often at the “end of their rope.”

Even after a diagnosis is made, that is just that start to a world that can be more about paperwork and waiting lists than a day at the park or a week’s vacation. Once parents move past some of the feelings of sadness, guilt and trauma, they find themselves searching for services that can seem unobtainable. Even when services are found, there can be a lack of qualified people to fill the positions which leads to even more frustration.

Other siblings in the household can often feel left out and have feelings of jealousy at all the extra attention their brother or sister with autism is receiving. Sibling support groups and special attention to their needs are need in more areas throughout the state.

It is often the family as a whole that is greatly affected by the diagnosis, whether it is the parent(s) running to an appointment for their child with autism or completing another piece of paperwork, or the aunt watching the child for a couple of hours so that the parents can have some time alone away from home. Aunts, uncles, grandmothers, and grandfathers are important sources of support and should receive as much education and information on autism as they can. Often a parent will get the “bulk” of the information, but a grandparent will be left out, only to learn more about the child by telephone every now and then. The community as a whole can do a lot to educate the whole family unit and provide the support groups for families that can be empowering for so many parents.

Finally, if anything can be learned, it is that families are strong and adaptable to the challenges and joys of having a child with autism, and are remarkable in the ways they have found to help cope with uncertainty and a diagnosis that still has no known cure. We have the power to affect change. Increased services are needed, more efficient ways of doing paperwork, and increased funding for respite and other services for parents who never go home from work like most people.

With education comes acceptance and support for the services many families are still desperately seeking. Now is the time to move forward and take another step towards solving the puzzle known as autism.

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APPENDIX A

Letter to Parents of Child with Autism (on University letterhead)

January 2002

Dear Parent:

My name is Adam Hutton and I am a Case Manager for the Penquis CAP Community Autism Services in Bangor, Maine. I am also completing my Master's degree in Human Development and Family Studies at the University of Maine. As part of my degree, I am required to do a research project. I have chosen to study the impact on the family of having a child with autism. This research will be used to gain a greater understanding of the various factors affecting families, and hopefully will lead to an improvement of services by our agency.

I am sending you this letter through the Autism Society of Maine because you are a parent of a child who has been diagnosed with autism. I would like to invite you to participate in a phone interview with me for this study. I am interested in interviewing the parent who serves as the primary caregiver. Participation is completely voluntary, and you are under no obligation to participate if you do not wish to do so. If you decide to participate, please know that you have the right to withdraw from the study at any time.

Participation will include a phone interview conducted at your convenience. The interview will take approximately one hour. The questions I will be asking are listed on the back of this form. I recognize that answering some of these questions could make you feel uncomfortable. Should this happen, please know that you are not obligated to answer anything.

To ensure confidentiality, please know that no identifying information will be connected with your responses. Each phone interview will be given a case number and will be described in my graduate thesis as "Case #1," Case #2," etc.

If you would like to be interviewed for this study, please call the Autism Society of Maine at 1-800-273-5200. This indicates you are consenting to have me contact you to be interviewed. The receptionist will take your name and number and pass this information on to me. I will contact you within two weeks to schedule the phone interview.

If you have any questions about this study, please feel free to contact me directly at my office: 973-3593. This is my direct line and you may leave a message on my confidential answering machine. You may also call my faculty advisor at the University of Maine: Dr. Sandra Caron, 581-3138. If you have any questions about your rights as a research participant, please call Gayle Anderson at the University of Maine's Office of Research and Sponsored Programs, 581-1498.

I would greatly appreciate your participation in this study, as I believe that information gained will be beneficial to our agency and to families who have children with autism.

Sincerely,

Adam Hutton
Case Manager
Penquis CAP Community Autism Services

APPENDIX B

Interview Questions

When was autism first recognized and diagnosed?

- 1) How did you first learn that your child had autism? And how old was the child?
- 2) When did you notice something was “different” or “not quite right” with your child?
- 3) Did you accept the diagnosis of autism or did you disagree/challenge/seek other diagnosis?
- 4) Please tell me about your reaction(s) when you first learned of your child’s diagnosis.

What is the nature of intervention services received by families of children with autism?

- 1) What services were put in place to help you? Were these difficult to obtain? If so, please explain.
- 2) How have you been treated with regard to your opinions and knowledge of your child’s needs by professionals (doctors, therapists, etc)?
- 3) What is the families involvement in the services (e.g., travel, attendance at meetings, paperwork, homework)?
- 4) How do you feel about the services? Are there any problems with the services you are receiving? If so, please explain.
- 5) What services have been most effective, helpful to your child’s development? What impact have the services had with regard to your stress/coping?

What has been the impact on the family of having a child diagnosed with autism?

- 1) What has it been like to parent this child?
- 2) How has the family dealt with this diagnosis?
- 3) In what ways has this impacted the family? (e.g., stress, coping, daily life, vacations, free time away from child)
- 4) If there are siblings: How has this impacted your other children, and your interaction with these other children? What have you done to try to respond to sibling’s needs?
- 5) If there are grandparents: How have they dealt with this child? How are they involved in the care of the child or as a support for you?
- 6) Other relatives/family members: How have other family members dealt with your child’s diagnosis? What role have they played?

BIOGRAPHY OF THE AUTHOR

Adam Michael Hutton was born to Gary and Dorothy Hutton in Cleveland, Ohio on October 1, 1974. He attended in Dover-Foxcroft, Maine: Morton Elementary School, Sedomocha Middle School, and received his high school diploma from Foxcroft Academy in 1993. Adam attended The University of Maine and received his Bachelor of Arts degree in Psychology in August 1997.

In September 1999 he enrolled in the graduate degree program in Human Development at The University of Maine. While working toward his degree, he served as a case manager in the Community Autism Services at Penquis CAP in Bangor, Maine. Adam is a candidate for the Master of Science degree in Human Development from The University of Maine in May, 2002.