EXPLORING FAMILIES’ REACTIONS TO THEIR CHILD’S DIAGNOSIS OF AN AUTISTIC SPECTRUM DISORDER

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ABSTRACT

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In light of the rise in rate of children diagnosed with an Autistic Spectrum Disorder in the last decade, many researchers have been trying to investigate the disorder that most people know as autism. Much of the research has been focusing on causes and treatment approaches. However, as is the case with every childhood disorder or syndrome, when a child is affected by an illness or a disorder, the whole family is affected, too. This present research aimed to investigate the effects of an autism spectrum disorder diagnosis on the family as a whole. More specifically, this research examined the effects of a diagnosis of autism across seven categories.

These categories included: 1) parents’ experiences of the diagnosis; 2) the effect of the diagnosis on the family; 3) effects on parents’ career(s); 4) effects on parents’ social life; 5) parents’ experience getting services; 6) experience with professionals and, last; 7) hopes, expectations and fears.

For the purpose of this research four parents (n=4) were interviewed. Findings from the interviews indicate that a diagnosis of autism affects a family’s life in various degrees, in the above mentioned categories. The findings also support past research that compares parents’ reactions to the emotional responses associated with Kubler-Ross’s Stages of Grieving.
CHAPTER 1: INTRODUCTION

“Richard was my miracle baby. The pregnancy went well, except for a tiny bit of spotting at about 5 weeks and a brief bout with morning sickness. At birth he was 7lbs 8oz, and 20 inches long, the size and weight the baby books considered exactly average. He had solid Apgar scores, first one a 9 and later a 10.

Richard was an incredibly good baby. He was sleeping through the night by the time he was 4 weeks old and would also take two well-spaced naps during the day. He rarely cried without an obvious reason for doing so, and I could take him anywhere and he would lie there cooing, smiling and charming the socks off anyone who would offer some attention. I remember one of my friends saying “Oh, you’ll never get another one as perfect as he is! You are soooo lucky!”

My son’s pediatrician began exhibiting concerns when Richard was 18 months old and was able to say only 4 or 5 words. I wasn’t worried at the time, having been assured by family and friends, “he’s your firstborn, and a boy, no less- he’ll talk when he’s ready. Maybe you should stop talking for him.” With that somewhat obnoxious bit of denial firmly in my pocket, I told the pediatrician that I wasn’t overly concerned and asked if we could just take a “wait and see” attitude.

Richard’s speech and language had not only not improved by his 24-month checkup, but he had lost the few words he had been able to say and was quickly retreating into his own little world. Looking back at photos of him during that period, I cried as I noticed for the first time the abrupt shift he had made from happy, engaging toddler to sad, lost little boy.

My optimism about Richard overcoming what I thought were simple “speech issues” was beginning to wane. I can’t recall my full range of feelings at the time, only that I felt a profound sense of dread.

Excitedly to finally have a useful lead, I called to make an appointment with our local pediatric neurologist, only to have to wait 3 months for the appointment. The wait was excruciating, and it occurred to me that once we finally saw the doctor, there would probably need to be several tests run before we were given a diagnosis. Wrong! Within 10 minutes of observing my son’s behavior in her office, the doctor looked at me incredulously and asked, “Don’t you know what this is? Look at him! He has autism!”

Definition of Autism

“There is no point in starting with the word ‘autism’ and then defining it. It is merely a word and like any other word it means just what we want it to mean - no more and no less” (Rutter, Schopler, 1978, p.3)

One can not embark in the quest of defining autism without starting with Leo Kanner’s work. In 1943, Leo Kanner published a paper based on his observations of eleven children, aged from 2 years 4 months to 11 years of age with a previously unrecognized syndrome. All eleven children, from the beginning of their lives, had demonstrated the inability to relate themselves to other people and situations. This was true, even though each case was somewhat different from the others in regards to the degree of the symptomatology, Kanner observed an “extreme autistic aloneness” present in all eleven cases (Kanner, 1943). The children’s inability to relate to others was accompanied by language delays, non-communicative speech, echolalia, perseveration, excellent rote memory and unusual sensitivities.

The symptoms of “inborn autistic disturbances of affective contact” as Kanner described the syndrome, could easily be misinterpreted as schizophrenia. However, Kanner, very mindfully distinguished the two disorders. “While the schizophrenic tries to solve his problem by stepping out of a world of which he has been part and with which he has been in touch, our children gradually compromise by extending cautious feelers into a world in which they have been total strangers from the very beginning” (Kanner, 1943, p.249).

In 1944, a Viennese physician, Hans Asperger, published a paper in which he presented the cases of four children who, even though they had striking social skill
impairments, their speech skills were rather sophisticated as were their problem solving skills (Asperger, 1944). Asperger’s work did not receive the attention it deserved until much later in the 1980’s, when Wing (1981) presented a publication of cases studies similar to Asperger’s and opened discussion on what is known today as Asperger’s Syndrome (Zager, 2005).

During the 1970s, Wing and Gould (1979) introduced the term “autistic spectrum”. A lot of criticism derived from that concept. Volkmar and Cohen (1991) argued that the so-called spectrum was simply hypothesizing that the disorders within the spectrum are continuous. Earlier on in this discussion it was mentioned that autism was initially often misinterpreted as schizophrenia, and autism was indeed classified under the psychotic conditions until the end of 1970s.

It was not until 1980 that autism was introduced in the third edition of the Diagnostic and Statistical Manual (DSM-III) as a separate diagnostic category under the Pervasive Developmental Disorder (PDD) label (American Psychiatric Association, 1980). By that time it was clear that autism was a unique condition. The diagnostic criteria DSM-III adopted to indicate autism included an early onset, impairments in social relatedness, atypical language and perseveration. The diagnostic criteria of the DSM-III reflected the classical early concept of Kanner’s infantile autism and, therefore, these criteria were highly specific and narrow (Zager, 2005).

DSM-III Revised (DSM-III-R) was published subsequently after a growing recognition that the previous edition was offering a limited reflection of autism. Autism was again under the label of Pervasive Developmental Disorders, along with Pervasive
Developmental Disorders Not Otherwise Specified (PDD-NOS) (DSM-III-R, 1987). This time the diagnostic criteria were overly inclusive and unclear. Thus, the criteria were once again revised, field tested and then published in the fourth edition of the DSM (DSM-IV). Autism was yet again under the PDD section, in conjunction with Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. According to DSM-IV the main attributes of the syndrome are the striking impairments in social interactions, impaired/delayed communication and a restricted repertoire of activities. (DSM-IV, 1994)

There has been a lot of controversy when it comes to the use of the terms “Autism Spectrum Disorder” (ASD) and “Pervasive Developmental Disorder” (PDD). Clinicians on the side of ASD (Wing, 1991; Gillberg, 1991) argued that the term “pervasive” is misleading as it implied that autism affected all aspects of development, whereas there were people with autism who had demonstrated typical development in selected areas. The term “pervasive” would only be appropriate in cases of autism where severe mental retardation occurred.

On the other side of the argument, clinicians in favor of the term PDD argued that “disturbances within autism and associated conditions are felt throughout the individual’s life and these difficulties pervade and affect virtually every area of activity and development” (California Department of Developmental Services, 2003, p22). The term “pervasive” was left to imply that all areas of development were affected to the same degree.
However, it is widely agreed that one of autism’s characteristics is the divergence between abilities and skills. Therefore, ASD has been the term that most clinicians have chosen to adopt to describe the disorder. For the purpose of this study the term Autistic Spectrum Disorder (ASD) will be used.

In summary, the definition of autism can best be described in terms of the following criteria:

1) An onset before the age of thirty (30) months.

2) Impaired social development, such as lack of attachment behavior, failure of bonding, lack of eye contact. The impairments in the social development are in turn affecting the child’s intellectual level.

3) Delayed language development. Specific features of the delayed language development include lack of social imitation skills, delayed meaningful use of objects, echolalia and pronominal reversal which also affect the child’s intellectual level.

4) Obsessive insistence on sameness, stereotyped play, perseveration and resistance to change.
Prevalence of Autism

Without a doubt the occurrences of autism have been on the rise for the last decade. Researchers have used the words “epidemic” and “plague” to emphasize the rates by which autism keeps increasing.

Fighting Autism is an organization with the goal to improve the quality of life for children with autism through research, advocacy, education and treatment. In November 2002 Fighting Autism published an autism prevalence report for the school years 1992 to 2003. This report aimed at quantifying the prevalence of children with autism in the public school system in the United States. The results of this report showed a systemic increase of autism cases across America. More specifically, in 1992 there were 15,580 students with autism enrolled in public schools in the U.S and outlying areas. In 2002, the number of children with autism had increased to 118,669. That is 103,089 new cases in a period of ten years. It should be noted that this report did not include children with autism who attend private schools or who are home schooled or who are in regular education classrooms.

The California Department of Developmental Services published a report in April 2003 discussing the changes in the California caseload for the years 1999 through 2002. In December 1998 there were 10,360 total cases of autism being served by the Regional Centers statewide. In December 2002 the number of autism cases had increased to 20,377. According to this report the population of children with autism increased by 634 percent between 1998 and 2002. This report did not include children less than three years of age, persons classified with less common forms of autism or children who are
suspected to have autism but are not yet diagnosed. An interesting finding from the California Department of Developmental Services report was the difference in the age distribution throughout the years. In 1987 the highest percentage of people with autism receiving services from the Regional Centers was in the 20 to 24 year old age range. However, in 2002, the highest percentage of persons with autism shifted to the 5 to 9 years old age range.

In order to visually demonstrate the rise in the prevalence of autism documented in the above mentioned study the following two charts were created to represent the dramatic increase (chart 1) as well as the shift of the age distribution (chart 2) of children diagnosed with autism.

Chart 1: Annual Growth in Number of Persons with Autism from December 1987 through December 2002
Groen, Grether, Hoogstrate and Selvin (2002) conducted a population-based study in order to investigate if changes in the diagnostic tools have contributed to the increased prevalence of autism cases. In their study, Groen et al., reported that the prevalence of "full syndrome" autism ranged from 5.8 per 100,000 for children born in the 1987 to 14.9 per 100,000 in 1994. According to the authors of this study, by the term "full syndrome", the Department of Developmental Services (DDS) defines cases where the syndrome first appears in children under the age of three and it is accompanied by severe symptoms such as extreme withdrawal and language disturbance. Interestingly enough, Groen et al., as did the California Department of Developmental Services report, found that the average age of children diagnosed with autism decreased across the years. In 1987, they report a mean age of 6.9 years which decreased to a mean of 3.3 years in the year 1994.

Another study examining the increase of autism prevalence was conducted by Blaxill in 2004. In his study, Blaxill reviewed a plethora of available prevalence studies.
and he too came to the conclusion that prevalence of autism has indeed increased dramatically in both the U.S and the United Kingdom. The rate of autism in the U.S once reported as <3 per 10,000 had increased by the year 2004 to >30 per 10,000. The same increase of prevalence occurred in the United Kingdom, as well. The rate of autism in the U.K. was once reported as <10 per 10,000 and in the year 2004 was almost 30 per 10,000.

Causes of Autism

There is an ongoing search for the cause of autism. To this date, not one cause has been able to be identified scientifically as responsible for the disorder of autism. Is it genetic? Environmental? Due to chromosomal anomalies? Prenatal influences? The effects of Thimerosal? Parenting? One could come across a myriad of causes in their quest for the etiology of autism. A great deal of research has been conducted, but, unfortunately there have been no reliable results. However, one of the most established named causes for autism spectrum disorders has been genetic liability (Rutter, 2005). According to the U.S. Department of Health and Human Services (2005), one of the underlying causes of autism is genetic factors. Unfortunately, it is not just one gene that is under investigation. Evidence estimates from as few as three to as many as twenty genes responsible for Autistic Spectrum Disorder or for some of autism’s symptoms.

Genetic factors linked to autism were cited in the report published in an issue of the Harvard Mental Health Letter (1997). The article discussed the likelihood of siblings of children diagnosed with autism to exhibit autism or milder related symptoms as 50 to 100 times higher than siblings of children without autism. In the same article, studies
have shown that parents of children with autism have undiagnosed mild autistic symptoms themselves. Based on twin studies the heritability of autism is estimated to be about 90% (Rutter, 2005, Harvard Mental Health Letter, 1997).

The truth of the matter is that autism is a multifactorial condition caused by multiple genes and some yet-to-be identified, non-genetic factors. The Autism Society of America explains that autism is a condition a child is either born with or is born with the potential to develop it. It is important to consider etiology as a dynamic framework. The symptoms of autism (self-absorption, communication difficulties etc) may be the symptoms of many other conditions, as well. Greenspan (2006) suggests the following analogy “consider a fever or an inflammatory reaction such as swelling. We know that many different causes can lead to fever or inflammation-- both are among the body’s limited number of responses to an infinite range of challenges” (p.20). In the same manner, Greenspan argues that the brain and the mind have equally limited responses (autism symptoms) as a response mechanism to a variety of challenges.

The “Autism Bomb”

Parents often describe the news of receiving a diagnosis of an Autistic Spectrum Disorder as a bomb that exploded and, with it, exploded the parents’ hopes and dreams. “The calendar of their lives was ripped off the wall and replaced by an uncertain future as they began intensive intervention to help their child, while they struggled to find hope and to regain their footing in life” (Ariel, Naseef, 2006, p12).

As professionals, we try our hardest to tailor the best services to each child’s needs. Our main focus and attention is revolving around the child with autism. However,
this child who we happen to see for a few hours a week also happens to have a family who is dealing with the emotional overload that comes with the diagnosis. In order for any treatment plan to be successful, professionals need to first help families deal with the diagnosis.

This study is an attempt to bring to light how the diagnosis of an Autistic Spectrum Disorder affects the parents' life and what it is like to raise a child with autism. Findings from this study will provide professionals working with children on the spectrum with a better understanding of each family's individual needs to help the children with autism unlock their true potential and reach their developmental milestones successfully.
CHAPTER 2: LITERATURE REVIEW

Welcome to Holland

"I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever go away... because the loss of that dream is a very very significant loss.
But... if you spend your life mourning the fact that you didn't get to Italy, 
you may never be free to enjoy the very special, the very lovely things ... 
about Holland”

(Emily Perl Kingsley, 1987)
Theory of Stages

Many researchers have established a theory of stages, according to which parents experience an array of emotions and feelings that has its starting point at the exact time their child’s diagnosis is being announced to them. These stage theories have their roots in Kubler-Ross’s Stages of Grieving. The number of stages of this model varies throughout the literature as some theorists agree on a four-stage model and others on a simpler model of just three stages. The most common four-stages models consist of the following stages: Shock, Denial, Sadness/Anger and, finally, Acceptance and Adaptation (Drotar et al, 1975, Gath, 1985). While investigating the process of parental adjustment to the birth of a child with a handicap, Blacher (1984) distinguished parents’ reactions three sequential stages: Initial crisis responses, continuing feelings and responses, adjustment or acceptance (Blacher, 1984, Eden-Piercy, Blacher, Eyman 1986).

Regardless of the number of stages, all theorists have agreed that once parents are faced with the reality of a child’s diagnosis, they are flooded with a myriad of universal emotional reactions. The starting point of all parents’ experience is characterized by shock and denial. Parents battle to come to terms with the child’s diagnosis, whether that may be Down Syndrome, Autistic Spectrum Disorder, mental retardation, congenital malformations or some other mental or physical handicap (Blacher, 1985). Before each child is born, the parents-to-be spend an extensive amount of time sharing their projected dreams of what their child will be like and planning the unborn baby’s future. The parents-to-be could be imagining a healthy little boy uttering “mama” and “papa”, running and jumping around the house, crying the first day at school, having tantrums during adolescence, leaving for college and being awarded a Nobel Prize in astrophysics.
Once a diagnosis is announced to these parents they are thrown into a state of shock realizing that their baby is not the imagined child.

According to Galinsky (1987), parents experience different stages while preparing for and entering parenthood, which she called “the Stages of Parenthood” (Galinsky, 1987). The above example of parents-to-be describes Galinsky’s “Image Making Stage”. Following the “Image Making Stage” is the “Nurturing Stage”. Even for parents of perfectly healthy babies, parents find it hard to believe that the baby actually belongs to them (Galinsky, 1987). There is a commonly-reported disconnect between the image the parents had and the child that is born (e.g., “I thought we’d have a girl, not a boy!”; “Where did that curly red hair come from?”). A diagnosis of any kind of problem could shatter the image created by parents and, in turn, have a negative impact on the formation of a relationship between parents and the baby. Parents with a handicapped child need to reconcile their imagined child with the child that is born. This is extremely difficult and requires time. Parents are shocked by the demolition of their expectation of a “normal child” more than the actual diagnosis (Blacher, 1984).

Each stage in this process of adaptation has its own timeline. Families and individual family members sort out their feelings in individual ways and on an individual timeline and, hopefully, find a way to cope with such issues when they can and in the way they are best able. After consideration of and adjustment to the initial shock of diagnosis and loss of their original expected child-to-be, parents of children with ASD experience the Stage of Denial and Disbelief. Parents may find it hard to understand the implications of their child’s diagnosis, what this really means (Garth, 1985). The act of denying the fact of the diagnosis is considered an attempt by the parents to escape the
trauma that the diagnosis has just brought into their lives (Drotar et al, 1975). During the Stage of Denial and Disbelief, parents have been noted to engage in “shopping behavior”. In an attempt to ease their pain, they “shop” or visit one physician after another in hopes of proving the original news as an initially false diagnosis.

Once the parents have had the chance to mourn for the imagined, normal child, they move to the next stage of reactions, which includes experiencing feelings of anger, sadness and guilt. Drotar and colleagues (1975) studied 20 mothers and 5 fathers while investigating the adaptations of parents to the birth of an infant with congenital malformation. According to the results of the study, seven of the twenty families were disrupted by feelings of anger. As one mother of a Down Syndrome child expressed during the interview for this study, “I never hated the baby. I hated what she was. I didn’t care if she died”. Parents also go through an emotional stage of blaming themselves for their child’s condition, even though the diagnosis was most often an “act of nature” (Blacher, 1984).

Gath (1985) reports of a father of a Down Syndrome baby who relapsed to his bachelor habits and lifestyle, dismissing his family responsibilities while waiting for the baby to come home from the special care unit. During the Stage of Anger and Sadness, it is not uncommon for tension to start appearing in parents’ marital and familial relationships, especially when family members are at different stages of grieving. When the mother is filled with sadness and the father is caught up in anger, it is hard for the couple to communicate and therefore comfort each other. Drotar and colleagues (1975) used the term “asynchronous” parental reactions to describe the phenomenon when each parent had different time duration at each stage. Even though asynchronous parental
reactions may cause strains on marital and family relationships, it is alternatively likely for some couples to become closer and become more supportive of each other, while adapting to the crisis of their child’s diagnosis, to come closer and become more supportive of each other (Drotar et al. 1975).

Adaptation and Acceptance is the final stage of the four-stage model and this period follows anger, sadness and guilt. Drotar et al. (1975) refer to this final stage as the “Reorganization Stage”. During the Reorganization Stage, parents reported more rewarding interactions with their children. They also report lower anxiety, higher enjoyment and increased comfort with their special needs child. In this final stage parents begin to accept their child as well as themselves and others. When parents reach this stage, they feel motivated and/or able to start obtaining information about programs and services to assist their child’s development. It is not unlikely for parents to also assume the role of an advocate in order to help other people with disabilities and special needs.

Featherstone (1980) stated that parents never reach an absolute stage of acceptance. They progress incrementally through a process that includes increasingly positive feelings about the diagnosis and their child with special needs, which appears to be the path that leads to acceptance (Blacher, 1984). Searls, (1978) states: “the shock, the guilt and the bitterness never disappear but stay on as a part of the parents’ emotional life” (p.27). A father of a child with many serious illnesses (seizures, hypoglycemic attacks) himself, Searls documented that he did not progress through the stages that many researchers outline. In contrast, he encourages professionals to discard the theory of
stages and progress, and to accept that negative feelings are part of parents’ emotional lives (Searls, 1978).

**Parents’ Reactions**

The limited available research on the issue of parental reactions to a child’s diagnosis of an Autistic Spectrum Disorder has established a number of common findings. First, studies have generally shown that the diagnosis of a serious disability affects the family and increases the stress level in family life. According to Norton and Drew (1994), the diagnosis of an Autistic Spectrum Disorder can either strengthen the unity of the family or weaken family relationships. They reveal that the stress of having a child with a disability may become a source for disputes and arguments, which eventually lead to marital conflicts and sibling discontent.

Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap and Plienis (1992) compared the stress profiles of mothers from different cultural and environmental backgrounds with children of different ages and different functioning levels. The aim of this study was to determine whether a specific pattern of stress can be distinguished among mothers of autistic children. The findings of this study demonstrated that certain subareas of stress were common and consistent among mothers, regardless of their culture, their environment, their child’s age or their child’s functioning level. These subareas of elevated stress included, first and foremost, concern about the autistic child’s future, followed by worries about the child’s cognitive ability to function independently and to be accepted in the community.
Another study designed to investigate how mothers’ and fathers’ perceptions of a child’s disability differ in relation to stress levels was conducted in 1991 by Beckman. Beckman (1991) studied parents with a handicapped child as well as parents of typically developing children. Fifty-four mothers and fifty-four fathers participated in the study. Half of the children (n=27) had handicaps whereas the other half of children had no handicaps. The children’s ages ranged from 18 to 72 months of age. Her findings revealed that mothers experienced more stress than fathers. The difference was not based solely based on the amount of stress between the parents, but also on the type of stress. As indicated by Beckman (1991), mothers tended to report more depression, insecurity in their parenting role and difficulty with their sense of competence. Fathers, on the other hand, reported problems with attachment more than any other issue.

The stress of an Autistic Spectrum Disorder diagnosis has been reportedly linked with increased levels of emotional distress for the parents as well as depression, anxiety and anger (Gray, 2002, 2002). Most predominantly with women, a child’s diagnosis was noted to have affected career choices, choices to be employed at all and/or career advancement and promotion. Gray, (2002), also reported the anxiety of the social stigma that a child with autism may bring to the family. Gray (2002) reported that many families have changed their social life style by limiting to disclosure of their child’s condition to others, and/or by restricting public encounters. Also, some parents chose to engage in family activities such as hiking and picnics, which entail minimal social interactions. Families expressed fear of social rejection and stigmatization because of the child’s diagnosis. They feared that their child’s behavior would lead people to criticize
the parents’ parenting skills and that parents would be accused of inadequate parenting (Gray, 1994, 2004, Norton and Drew, 1994).

An interesting point in Gray’s (2002) investigation of parents’ experience of stigma, were the considerable differences between responses of fathers and mothers. It was pointed that mothers were more likely than fathers to report “felt” stigma (used to describe feelings of shame). However, the differences between the sexes were greater in “enacted” stigma (referring to instances of overt rejection). When it came to “enacted” stigma, mothers had, by far, encountered more instances of hostile staring and rude remarks.

Another factor influencing the amount of stigma experienced by parents was reported to be the child’s symptoms (Gray, 2002). For example, according to this research, the more aggressive a child was, the more s/he attracted hostile stares, which resulted in higher incidents of reported stigma.

In 1979, De Myer studied the impact of autism on the family along a number of dimensions. In this study, failures (lack of human relatedness, difficulty with daily activities such as feeding, dressing and toileting) of autistic children were shown to have an impact on each parent individually. There failures also affected marital relationships, sibling relationships, as well as parent- autistic child relationships. De Myer also found that in more than half of the families participating in the study, the marital relationship was intensely affected by the rearing of an autistic child and one-quarter of those families expressed thoughts of divorce.

Rodrigue, Morgan and Geffken (1992) focused their research solely on the psychosocial adaptation of fathers of developmentally disabled children, including
perceived parenting competence, perceptions about marital and family functioning and social support. Rodrigue and colleagues (1992) compared 20 fathers of children with a diagnosis of Down Syndrome and 20 fathers of typically developing children. Even though the fathers of developmentally disabled children reported more disruption in family planning as well as increased financial burden, interestingly enough, no significant difference was found between fathers of developmentally disabled children and fathers of typically developing children on perceived parenting competence, marital satisfaction and social support. The three groups of fathers did not differ significantly in their levels of perceived parenting efficacy: all three groups fell within the normative range. An interesting finding of this study showed fathers of developmentally disabled children to report parenting more satisfying when the disabled child was a boy rather than a girl.

Culbertson (1977) studied the helpfulness of professionals to families of autistic children. Even though Culbertson examined a small population (n=10 families), the results of the study suggested that the process of reaching a diagnosis and establishing a treatment plan was perceived by the families to be a depressing one.

**Siblings’ Reactions**

Family is not constituted of only the parents and the autistic child. There is the immediate family that includes other siblings, and the extended family which is comprised of grandparents, uncles, aunts, nieces and nephews, etc. Unfortunately, the research focusing on the reactions of siblings of individuals with Autistic Spectrum Disorders is rather limited.
The Autism Society of America recognizes that an autistic child can be a potential source of stress for the non-autistic siblings. Among the stress sources identified in their website, as provided by Adrianne Horowitz, CSW, Director of Family Services for the Eden II Programs for Autistic Children, embarrassment around peers, jealousy regarding amount of time parents spend with their brother/sister, trying to make up for the deficits of their sibling with autism, concern regarding their parents stress and grief and concern over their role in future caregiving are mentioned (www.autism-society.org).

Research findings regarding siblings' reactions to a diagnosis of autism have been inconsistent. Some findings support that autism has a negative effect on siblings, including increased loneliness, difficulty understanding the autistic sibling's behavior, depression and sibling interactions that are less reciprocal (Rivers & Stoneman, 2003). On the other hand, Bagenholm and Gilberg (1991) found that siblings of autistic children are more likely to view their sibling relationship positively (as cited in Rivers & Stoneman, 2003). Bristol and Schopler (1984) found that typically developing siblings feel proud of teaching their younger brother or sister with autism (as cited in Rivers & Stoneman, 2003).

Crnic, Friedrich and Greenberg (1983) conducted and published a study exploring how families adapt to children with mental retardation. The study examined coping mechanisms and stress in families with mentally retarded children. Crnic et al. (1983) investigated the effects a mentally retarded child has on the siblings. In their literature review, they refer to an early study by Farber (1960) who interviewed siblings of mentally retarded children and found that female siblings were seen as surrogate mothers for the retarded child. The study by Crnic and colleagues concluded that the effects of a
mentally retarded child has detrimental effects on the non-retarded siblings, especially on the female siblings, which involved higher levels of stress and anxiety, conflicts with parents, as well as lower sociability (Crnic et al., 1983).

Bibace and Walsh (1979) used a developmental framework to explain children's progression of comprehension of health and illness, based on Piaget's stages of development (as cited in Glasberg, 2000). According to Piaget, children on the Preoperational Stage (2 to 7 years old) use mostly symbols and mental representations to make sense of the world. Children's thought during this stage is mostly empirical rather than logical. Bibace and Walsh's (1979; 1980) research suggests that children during the Preoperational Stage respond to questions either nonsensical or they do not respond at all.

The next stage in Piaget's theory is the Concrete Operational Stage (in children 7 to 10 years old). At this stage children start to conceptualize, creating logical structures that explain his or her physical experiences. Children are able to differentiate their thoughts and thoughts unrelated to them. At the final stage of Piaget's framework, the Formal Operational Stage (in children 11 to 15 years old), the child's cognitive structures are like those of an adult and include conceptual reasoning. Bibace and Walsh (1979; 1980) argued that children during this stage described illness as a result of a malfunction of the body, but their responses were lacking information. As the children grew to realize the influences of the brain on the body, a deeper understanding of illness emerged.

Glasberg (2000) conducted a study exploring the development of understanding of autism in siblings of individuals with an autistic spectrum disorder, utilizing Bibace and Walsh's framework. A total of 63 siblings were interviewed for this study and they were separated in different groups according to their age (20 five- and six-year-olds, 22
seven- to ten-year-olds and 21 eleven- to seventeen-year-olds). More specifically, Glasberg’s Preoperational Stage children appeared to respond similarly to those in Bibace and Walsh’s study. During the Preoperational Stage, children appeared as they had no awareness of autism’s impact on their lives or their siblings. For example, when the interviewer asked “How does PDD (Pervasive Developmental Disorder) make your sister’s life different than it would be without PDD”, a child answered “I know how to spell my sister’s name” (p155). So, if a child is asked about autism during this stage it is likely to respond “I don’t know” or give an answer irrelevant to the question.

For the Concrete Operational Stage, this study showed that children between the ages of 7 and 10 were likely to describe more than one effect of autism on their sibling. Children were able to understand how a symptom can affect their sibling. The following example demonstrates the above. The interviewer asked “How does autism make your sister’s life different?” The child replied, “Well, it’s hard for (name) to talk. She doesn’t have too many friends, and she can’t go to the regular school” (p155).

At the Formal Operational Stage, Glasberg’s participants were able to think about possible events. “Will Traci’s life be different as a grown up because of Asperger’s?” “It all depends on what she learns; if she learns how to make friends, maybe she can get a job and a husband or family, if not, no” (p155).

The results of the study showed that children’s understanding of the implications of autism seem to follow Bibace and Walsh’s Piagetian framework. However, the children interviewed for this study appeared to acquire concepts regarding the definition and etiology of autism at a much slower rate than the illness study. The author explained that this might be due to the fact that children live imbedded with the implications of
autism daily whereas when it comes to defining autism, children cannot articulate the
classification of ASD. They do not hear other people describing autism but they see the
effects of autism on their siblings every day. Piaget (Glasberg, 2000) supported that
emotional burdens can affect children’s cognitive development and cognitive processing.

Rivers and Stoneman (2003) conducted a study investigating the effects of marital
stress on the relationship between children with autism and their siblings. According to
the authors family stress and coping can affect the quality of sibling relationships. In their
study fifty family triads participated. Each triad consisted of a parent, an autistic sibling
and a typically developing sibling. Through self-report inventories and questionnaires,
the researchers found that when marital stress was higher, typically developing siblings
reported less satisfaction in their relationship with their sibling with autism. Adding to the
above findings, typically developing siblings reported expressing more negative
behaviors and less positive behaviors towards their autistic sibling. As indicated by the
authors, typically developing siblings’ display of negative exchanges with their sibling
with autism reflected the negative exchanges seen in their parents’ relationship.

Kaminsky and Dewey (2001) investigated sibling relationships of children with
autism compared to children with Down Syndrome and typically developing children.
The results of their research indicated that siblings of children with autism reported less
intimacy and less nurturance in their sibling relationship that siblings of children with
Down Syndrome and siblings of typically developing children. The authors presumed
that the above may be so, due to the variety of social deficits related to autism. An
interesting finding in Kaminski and Dewey’s study was the levels of admiration that
siblings of both children with autism and Down Syndrome reported. Siblings of children
with disabilities reported greater admiration for their sibling’s accomplishments than siblings of typically developing children. In this study it was indicated that siblings of children with disabilities did not report feeling that their parents favored their disabled sibling.

Depression and social adjustment in siblings of boys with autism were studied by Gold (1993). Gold compared 22 siblings of autistic boys and 34 siblings of typically developing boys on measures of depression and social adjustment. Through the means of questionnaires and parent interviews, Gold found that there is no significant difference in social adjustment in the two sibling groups. However, siblings of autistic boys scored higher on the depression measure than siblings of non-autistic boys. Siblings of autistic boys scored high enough on the Children’s Depression Inventory (CDI) to consider them depressed. The results of this study also indicated sisters of autistic boys scored higher on the CDI than brothers of autistic boys.

**Grandparents’ Reactions**

Parents of an autistic child or a child with other disabilities are very likely to seek support from the child’s grandparents. The role grandparents play in the raising of a child with disabilities has been referred to as “...a vital factor in a therapeutic approach” for the disabled child (George, 1988, as cited in Glasberg, Harris, 1997, p18).

“When our grandson was diagnosed with autism, we were devastated, frightened and ignorant” (Anthony & Anthony, 2001, p8). As parents face their own feelings of loss, likewise, grandparents are likely to face feelings of loss of the grandchild they had
imagined. Grandparents are also likely to experience feelings of pain around the difficulties their children are living through raising an autistic child (Freedman, 2001).

A study conducted by Harris, Handleman and Palmer (1985) investigating how parents and grandparents viewed the diagnosis of autism and how the diagnosis impacted the family revealed significant intergenerational differences. Both maternal and paternal grandmothers were found to take on a more positive view of the grandchild’s diagnosis than the parents did. A Greek proverb declares “my child’s child is twice as much my child”. Taking this saying into consideration, one can understand grandparents’ supportive response to a diagnosis. Their genuine care and love for the grandchild assists them to see beyond the diagnosis and to think of ways to help their grandchild flourish. In the eyes of most grandparents, all grandchildren are perfect.

Glasberg and Harris (1997) conducted a study in which 227 parents and grandparents participated (61 mothers, 52 fathers, 42 maternal grandmothers, 28 maternal grandfathers, 30 paternal grandmothers and 14 paternal grandfathers). The aim of the study was to evaluate how parents and grandparents assess the development of their child with autism. The results of this study revealed that maternal grandmothers were more involved with the grandchild with autism than the other groups of grandparents. On the other hand, paternal grandparents appeared to be least engaged with the family. Another finding of this study indicated that maternal grandparents were more familiar with the grandchild, and they also assumed the role of caregivers more often that the paternal grandparents.
CHAPTER 3: METHODOLOGY

This current study used parent interview data to investigate the effects of a child’s diagnosis of autism on parents. The hypothesis of this study was that a diagnosis of autism affects the entire family. This is a study using qualitative research methods, exploring the degree to which and the ways in which parents describe the effects of the diagnosis on the family. An understanding of the effects of autism on the family could possibly lead professionals to consider and collaborate with the family as a whole when providing services to a child with autism and include the family when designing, implementing and evaluating a therapeutic plan.

The participants included in this research were parents of children who have been diagnosed with an Autistic Spectrum Disorder, either by the North Los Angeles Regional Center or the Los Angeles School District. The study was originally designed to employ written parent questionnaires to gather the desired data (see copy of questionnaire in Appendix A). This initial study methodology and protocols were approved by the CSUN Human Subjects Committee in November, 2005. However, the initial rate of return of parent questionnaires was too low for the purposes of this research (n=12 questionnaires returned out of 150 questionnaires distributed over a period of four months). Therefore, the present researcher re-designed the study utilizing parent interviews and the amended study methodology was reviewed and approved by the CSUN Human Subjects Committee on May 5th, 2006.

The participants were either clients of the McRory Pediatric Clinic or contacted through a referral from other professionals in the greater Los Angeles, California area who had been informed of the study and had asked their parent clients if they would be
interested in participating in this study. The participants were initially contacted by phone. During the phone conversation the parents were informed of the purpose of the study as well as what to expect from the interview process (duration, place, bill of rights etc). Once parents agreed to participate, the interviewer set an appointment with the parents to be interviewed at their homes. The duration of the interviews was from one hour to one hour and forty-five minutes.

Parents completed informed consent forms. The interviews were audio taped upon parents’ consent. The interviews started with the interviewer explaining to the parents their rights for participating in this study. The interviewer went one-by-one through the items on the Experimental Subjects Bill of Rights. The parents were also assured that their responses would be treated with complete confidentiality and that no real names would be revealed at the study (See copy of interview protocol and related materials given to parents in Appendix B).

The issues that were covered in the interviews included the onset of symptoms, the referral experience, diagnosis, and the effects of the child’s diagnosis on the family as well as the child’s present symptomatology.

Three mothers and two fathers agreed to be interviewed (n=5). In one family, both parents agreed to be interviewed. The other three participants were a single father and two married mothers. The parents’ educational background varied from high school degree to graduate degree. The children of this study had a mean age of 5.6 years.
CHAPTER 4: RESULTS

Introduction

This chapter presents results of the study and, further, provides data analysis of the interviews focused on four parents’ responses across seven categories. These categories include: 1) parents’ experiences of the diagnosis; 2) the effect of the diagnosis on the family; 3) effects on parents’ career(s); 4) effects on parents’ social life; 5) parents’ experience getting services; 6) experience with professionals and, last; 7) hopes, expectations and fears.

First, responses from each family individually are presented and subsequently findings will be compared and contrasted across the above-mentioned seven categories. In order to respect families’ anonymity, all names have been changed.

Sample

Initially, five parents were interviewed for this research; three mothers and two fathers (n=5). However, one of the mothers asked via telephone to have her interview deleted from the data, due to personal reasons she did not want to disclose to the interviewer. Therefore, the total of participants decreased to four (n=4). The following data analysis is based on the responses of the four parents.
Case By Case Description

Case I: Cathy and S (see notes in Appendix C)

Personal Description

This is a family of five. It consists of a mother, a father, an eight-year-old son with autism and a set of baby twins. The mother is a full-time mom and the father is a business owner. The parents have been married for eighteen years. The mother, “Cathy”, was interviewed.

Diagnosis

The family received an official diagnosis of autism when their son was five years old. However, Cathy talked about concerns she had about S since he was 3 months old; her son was an in vitro baby and he was born prematurely. At the age of 18 months, the son’s reported delays in development raised concerns in the parents. They addressed their concerns for their son’s language delays with their pediatrician and they were referred to a pediatric neurologist who diagnosed the son with hypotonia and apraxia.

During his school district evaluation at the age of three years, this child received a diagnosis of Developmental Delays with the goal of qualifying to receive services. At the age of five years, the young boy received an official diagnosis of autism by a neuropsychiatrist who told the family “there is zero doubt that he is autistic”. Cathy described the news of the diagnosis as “to me it was almost a relief...because I didn’t have to walk around saying to my husband all the time; ‘S has autism. There is something wrong with S.”
Effects on the Family

“I was estranged from most of my family until S got his diagnosis at the age of five [years]. My husband’s family was of no support whatsoever. I remember my husband’s father saying that S’s problems were the result of poor parenting”.

Cathy admitted that even though initially neither of the couple’s families was of any support, the last few years’ relationships appear to be mending and they feel more involved with the rest of the extended family. Also, most of the support for this mother came from other friends with children with autism. “Friends become our chosen family and that’s my philosophy in life. I’ve basically found my own support.”

When Cathy was asked about the effect of the diagnosis on her marriage she replied that had the couple not been married for 10 years prior to having S, she is not sure whether her marriage would have survived. “I think we have weathered a lot of storms—miscarriages, infertility and other things—before doing autism. I think if we had not weathered all those things, we would not be here because it’s too stressful. The daily stress of autism is too much, the meltdowns, the planning, the aggression, the screaming.”

Effects on Career

Cathy has a degree in Child Development and a master’s degree in Marriage and Family Therapy. Even though she has never worked outside the home, there had been times after having S when she considered going back to work but decided not to as a great deal of her time is consumed by taking S to therapy. “Who is going to run this place? I need to stay on top of what’s going on. I wouldn’t have known the things that were going on at the school unless I went there all the time to observe”.

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Social Life

Ever since S’s diagnosis the family’s social life has changed. This is a family who initially used to go on family vacation, go to temple, enjoyed dinners at restaurants and other family outings. However, as S grew older, he started demonstrating some challenging behaviors such as aggression and screaming, making it hard to plan for a family outing.

Another factor that has affected this family’s social life has been the number of hours S spends in therapy. “A lot of our time is spent doing therapy, making accommodations for S. There are a lot of things that we can’t do. Every decision is based on. ‘Can S handle it?’”

Experience getting services

According to Cathy, it was a friend who suggested she call the Regional Center and ask for speech therapy and occupational therapy. The mother remembered it was rather stressful trying to get services for her son, especially when he turned three years old. The transition from Regional Center to the school district referral process and services system was overwhelming, as neither of the agencies wanted to recommend and provide services to her child. S’s parents had to go through the mediation process in order to get the services their son needed.
Experience with professionals

"I wouldn’t say I’ve had a good experience with professionals. Everyone has a different suggestion for me. It’s very hard to get people to be part of a team.” Cathy described how frustrating it was to actually get all therapists and professionals to agree on the diagnosis. It was extremely frustrating getting different diagnoses from different professionals before S was even three years of age. Cathy expressed her wish for a team approach. “I am the team” she said, as she is the one that coordinates S’s therapies, activities and education plans.

Hopes, Expectations and Fears

Cathy hopes that one day S will be able to live independently and that he continues to make progress. The family understands that as S grows older new challenges will come their way, but they are ready for them. She specifically referred to puberty; “Puberty seems to be the time when they can go one way or another” implying a potential future regression in her son’s progress.

Cathy’s fear is that S will have to live with her for the rest of his life. She expressed her concern in regards to S’s aggression and its effect on his twin siblings. She is worried that “he’ll have to be placed in a residential placement because I won’t be able to manage him.”
Case II: Peter and L (see notes in Appendix D)

Personal Description

“Peter” is a 44-year-old divorced male. He is a business owner and at the time of the interview he shared custody of his five-year-old son, “L.” who just recently received a diagnosis of “high functioning” autism. According to Peter, even though L’s mother shares custody, she has not been actively involved in L’s life. Peter expressed concerns of L being exposed to a physically violent environment because of custody arrangements, when at his mother’s house.

Diagnosis

It was L’s teacher who first expressed some concerns regarding L’s speech, when he was two years old. Peter initially thought that L’s delays were somewhat related to the fact that he and his wife were going through a divorce. At the age of three years, L started speech therapy and around that time Peter took L to a psychologist. The psychologist told Peter “I’ve seen a lot of children of divorced parents and this is not the case. This is not the case of a divorce and not the case of environmental delay. There is more than that.”

When Peter finally got a diagnosis of autism he felt relieved. “I think I was relieved...’This is it’. ‘This is what I have to deal with’ and then I knew what I had to deal with, now I know what to do.”
Effects on the family

Peter and his wife had difficulties within their marriage prior to L’s diagnosis, so there is no indicator that the diagnosis caused friction in their relationship. Peter’s family has been very supportive over the course of time but, unfortunately, his entire family lives in a different country. Even though the thought of moving back to his country has crossed Peter’s mind, he stays in the U.S. in hopes of providing L with the best possible services. “My support system is not as good as I wish it was, but academically L is going to be OK here, and also socially he’s going to be OK.” During the interview, Peter said that he is not seeking a girlfriend or a wife at this point as his main focus and priority is his son.

Effects on Career

Peter is the owner of a small business that has been doing well over the years. Peter revealed that he has not been able to work as much as he wished he could since L was diagnosed with autism. Peter confessed that he has difficulty trusting the care of his son to other people. In order to take care of him, Peter has been cutting down his work hours. “Financially, when L was born, this house was cleared and I was clear of any debt. Today I owe $470,000. A big part of it was the divorce that got super expensive, but, the fact that I was a single father and the primary caregiver and I took the role of the female and the male in his life actually deprived me from the ability to work.”

Even though Peter has not been satisfied with his business’s progress the last couple of years he keeps a positive attitude by stating “I can always work. I can always make money, but, L is going to be a little child only once.”
Effects on Social Life

Peter, by choice, does not have a social life. His only priority is his son. “I could not sit down and wait for someone else to take care of my son. He’s my only child and I had to take care of him.” He claimed he has had no interest in going out and having fun. “The reality was that I was taking him to school and I was doing all the things that I was doing and I was working and I was actually cancelling my life for that.” Peter has no regrets for not having a social life. To him, spending time with L is far more important. “I like everything I do with him. Just to wake him up in the morning is a pleasure; putting him on the bus, telling him that I love him, blowing him kisses and him catching them.”

Experience Getting Services

When it came to getting services for L, Peter demanded what was rightfully his. He received all the services his son needed, even if it meant paying out of pocket. Peter appears to be L’s greatest advocate. He knew what services he wanted and needed and he made sure the people at the Regional Center and the school district provided those services. “Why should I wait for the services to be given to me? If I have already been approved [regarding] what I should do, and that’s a difference between me and some other parents, I’m not sitting down. I should go right away to the agency, hand them the IEP and tell them, look, I’m approved for 30 hours a week. Why don’t you already start providing the services?”

It should be noted that during the interview Peter confessed that he believes that partially the reason why some agencies have denied services has been his cultural background. “I have difficulty presenting myself. I have a thick accent and people might
think... When I went to look for speech therapy for L, I was rejected flat out from any place that I went. I believe that the first reason was my accent. The other reason was that [the custody arrangement for] L was one week with me and one with his mother. Although they could have done that [accommodated to that schedule], if it was a little difficult, they wished to avoid it.”

*Experience with Professionals*

When Peter was asked about his experiences with the professionals in the field, he claimed that he has been very satisfied. All the professionals involved in L’s case have been of extreme support to Peter and he actually considers two of those professionals as close friends. “I’m very lucky. In this case, I’m very lucky!”

*Hopes, Expectations and Fears*

One of Peter’s greatest expectations of L is that when he turns 28 he will be working on his doctorate degree. He hopes that L will grow up fully equipped with all the necessary tools to succeed in his life. “I know that I’m 44 and I’ve got about a good 25-30 years to provide for this child. And I need [to realize] by the time that I’m going to be gone; I need to make a situation that this child who is going to be a grown up man, is fully prepared, step on his two feet and deal with the world.”

Peter emphasized the importance of academics several times over the course of the interview. He believes that students with better grades have a better social status.

In regards to fears, Peter is afraid that L will not be taken care of properly.
Case III: Susan, Jack and E

Personal description

Susan has a bachelor’s degree and is a stay-at-home mom. Jack is an attorney and he is the provider of the family. Susan and Jack have two children; “E”, a five-year-old boy with a diagnosis of high functioning autism and a little girl, who is almost three years old, who is without a related diagnosis. Each parent was interviewed separately.

Susan and E (see notes in Appendix E)

Diagnosis

Susan and her husband’s initial concerns were in regards to E’s speech and language. E had demonstrated some delay in his speech development and therefore when E was 2 years 4 months they sought the expertise of a speech pathologist who suggested “you may want to contact the Regional Center to schedule an evaluation”. Susan recalled that the day the Regional Center assessor came over to see E “she got to see the worst”.

Before E turned 3, Susan and Jack looked for a second opinion, so they made an appointment to see a child psychologist with an acclaimed reputation. The day they met with the child psychologist to go over the results of her assessment, Susan remembered fighting really hard to get the diagnosis of autism. “I swear if I hadn’t spoken up we would have gotten PDD (pervasive developmental delays), we would have gotten DD (developmental delays). We kind of talked her into giving us a diagnosis.”

Even though Susan fought hard to get the diagnosis, when the child psychologist finally gave them the autism diagnosis, Susan felt devastated. “I was highlighting all the negatives, hand flapping, toe walking and she was right. But hearing her say it...It’s like,
I don’t know, you’re fighting with someone and you say I don’t want to be your friend and they go alright and you just don’t want to hear that...you almost want them to say no, he’s OK.”

Immediately after Susan and Jack left the doctor’s office she recalled crying in the parking lot with her husband. However, the upsetting news was accompanied by a sense of relief because finally they were able to put a name to their child’s behaviors and they knew they were going to access services for E.

Before E’s diagnosis, Susan always thought of autism as “a child banging his head against the wall, no language, no nothing. I had no idea.” Susan still struggles to differentiate between typical three-year-old behaviors and autistic behaviors. “When it’s your first-born you don’t know. There are a lot of things that E does that’s just typical kid stuff and I don’t know that. I think it’s weird.”

**Effects on the Family**

Susan and Jack needed their privacy when they first got the diagnosis. They did not want to share the news with anybody else until they were ready to accept the diagnosis themselves. “At first, when we first found out, we didn’t want anybody to talk about it to us, we didn’t want to know. We didn’t want anyone’s opinions about it. We needed to process it on our own in isolation within our nuclear family.”

When Susan disclosed E’s diagnosis to members of their extended family “they said ‘oh we thought something was up because we’ve never been able to connect with him and we didn’t know why.’ That really bothered me. I was really angry at them that they also thought there was something wrong.” While Susan was reflecting on her anger
towards those particular family members she mentioned that probably even if they had brought up their concerns to her right then, she would not have listened to them.

In regards to her family, Susan stated that she is fortunate enough to have her parents’ support and love throughout the entire process of the assessment and the diagnosis.

**Effects on Career**

Susan has a bachelor’s degree in Public Administration and she used to work in advertising, “a really fun job” as she described it, before she had E. She stopped working when she had her son but that had always been her intentions. “I stopped working when I had E which we always had planned to do. I was always going to be a stay at home mom for a while and then go back.” She had not had a chance to go back to work yet and partly is because she needed to make sure she was actively involved in E’s therapy sessions. “I couldn’t work. I went to tons of therapy. That’s what I did. That was my full time job.”

Nevertheless, Susan is thinking of going back to school. She is considering getting a master’s degree in Social Work and then seeking a job as an advocate for families with children with high functioning autism.

**Effects on Social Life**

When Susan was asked about her social life after the diagnosis she admitted that it has indeed changed a lot because of the diagnosis. More specifically, “I just want to be a mom and meet people for coffee, go out for dinners with friends. We don’t have a lot of
friends. We have friends that we had before this and we’re still friends, but I can’t meet them. I’m gone. I’m in therapy and their problems, to be honest, are so trivial.”

Susan has found an amazing amount of support through her support groups. She has joined a support group for parents with children with autism and she feels that she can relate to her support peers easily. “I love support groups. Knowing I’m not alone. Without the support of these amazing women, that was huge. That group really helped me.”

As Susan was describing the changes in her social life she did not seem to miss her past life style. On the contrary, she felt that the diagnosis of autism has brought her a better understanding of priorities and has forced her to be a better person. “Autism dramatically changed my way of looking of life just as a person, because it forced me to re prioritize everything in my life. It really changed my whole psychology make up, if you will, and it forced me to have healthier priorities. Maybe that’s what happens to people who almost die.”

Experience Getting Services

As Susan recounted her experiences accessing services for E she kept repeating what a difficult and overwhelming task it has been. However, she was fortunate enough to receive all the services they needed. “I don’t even know what to say. It’s been difficult, but we always got what we wanted. We got everything we ever wanted for E. Difficult because people were saying E doesn’t need anything.” Susan believes that the fact that E has high functioning autism had been responsible for the initial difficulty of receiving services. Professionals who did not have a clear picture of E and who based their
assumptions on written reports found it difficult to agree on providing specific services for this child.

Susan shared a painful experience with a professional during E’s first IEP (Individualized Education Plan). The professional who attended E’s IEP, completely disregarded the Regional Center psychologist’s diagnosis of autism by claiming to everyone at the meeting “if E is autistic I will shoot myself”. Susan recalled how frustrated her and her husband left from that meeting. They were unsure who to believe. On one hand the Regional Center psychologist had given them a diagnosis of autism and on the other hand this other professional was so certain that he was not on the spectrum that she was willing to shoot herself. She described the IEP experience as “scary and frightening.”

The support group has been of incredible value to Susan as it has helped her to become a better advocate for her son. She keeps learning from other parents and the attorney they eventually hired to assist them in issues regarding how to go about and demand services for her son.

Experience with Professionals

For this family, finding the right professionals to work with E had been a rollercoaster of an experience. Susan and her husband enrolled E in several therapeutic programs which at the end appeared to not be as beneficial for E as expected. “I kept leaving programs”, “He was the best in the room and he didn’t need to be there.” Susan, looking aside the initial difficulties with finding the right matches for E, she is presently extremely happy with all the professionals working with her son.
She expressed her gratitude for her developmental pediatrician. He was the one who initially expressed some concerns in regards to E’s language development. Susan recalled how her pediatrician kept on counting E’s words.

*Hopes, Expectations and Fears*

Susan’s main hope for E is to have a happy life. “I hope he has a happy, easy life. That’s it. I just want him to fit in as much as he can which I think he does more than some do anyway. I just want him to be happy. I don’t want him to have difficulties or pain or suffering.” Susan expressed concerns about E attending kindergarten but at the same time she tries to not worry about the distant future. Susan used a quote that according to her seems to fit perfectly with a family living with autism “There are two places you have no business living in; the future and the past. You have to live in the present.” She explained that by living in the past all one gets is pain and by worrying about the distant future takes away from precious moments of the present.

**Jack and E** (see notes in Appendix F).

*Diagnosis*

When Jack and Susan decided to become parents they agreed that they were going to have an amniocentesis done to make sure their child would be “free of things”. They were already in agreement that if their embryo was diagnosed with any disorder or syndrome, they would terminate the pregnancy. They were determined to have a healthy baby. The reason was partly because of family friends who have a daughter with Down
Syndrome and their entire life has been revolving around this child. Jack and Susan did not want that kind of life for themselves so they took the precautions they needed to take.

Jack described E always being slightly on the slow side of development. Around E's second birthday, their pediatrician expressed some concerns in regards to E's language and speech, and suggested they have E evaluated by the Regional Center. Due to Susan being pregnant at that time, they postponed the evaluation for almost a year.

When the Regional Center psychologist told this family that E might be autistic, Jack had difficulty accepting the diagnosis. "We have this diagnosis now and I don't have this devastation because his diagnosis is based on a man who has never met my son."

Jack and Susan hunted for a second opinion and they found themselves in the office of a well known and respected developmental pediatrician. According to Jack, the pediatrician recognized some deficits in E's development but she admitted to the family that she was not entirely positive about the diagnosis of autism. She notified the parents that the main reason she gave E the diagnosis of autism was so that they could receive the services he needed.

Jack expressed: "there is a sense of secrecy. My wife says denial. I think my wife would say that I was in complete denial. I think I might have been in denial outwardly, but I knew what I knew in the inside, but I wanted to be optimistic and I didn't want everything to be negative. For me the negative would be defeat and I don't think I could work from there. If I see defeat I might give up so I can't go there."

The initial news of autism brought worry and concern to Jack. Up until that time his knowledge of autism was limited to "bad and trouble". He worried whether he would be able to take care of this child and his needs. "I have no idea how to take care of him. I
don't know if I’m going to have the ability to do that. Emotionally or intellectually or financially, anything, I just didn’t know if I was going to be able to do it.”

Jack now admits that the diagnosis has changed his perspective about life and people. He considers himself a better man and a better father because of the diagnosis. “As a result of this diagnosis I have become more patient with my son, obviously, and with other people. I look at people and say there are things we don’t know about people, and I believe I am much more patient. I have become a much better father, more attentive, more appreciative of successes.”

Effects on the Family

Jack expressed how lucky he has been with the support he has received from his family. He described how his mother is “insanely devoted” to E and how his father loves both his children. He admitted that initially his wife, Susan “had to explain some things to them in the beginning” but overall, he thinks his family has been great helping them deal with the diagnosis of autism.

Jack also described how valuable “Sarah”, E’s baby sister, has been in E’s life. Especially, as Sarah is getting older, Jack sees a wonderful connection between the two siblings. When Jack was asked if the children are treated differently he answered “they are treated the same. He is treated more that she is. More severely and harshly. Not because he is autistic, but because he is older.”
Effects on Career

Jack is the provider of the family working full time for a private company. He admitted that he has been staying at work a little less since they had E and Sarah. He is grateful for the job he has, being able to provide for his family and allowing his wife to be a stay-at-home mom. Jack also expressed his great fortune to have an understanding boss. “I happen to have a great boss. First of all, he never believed that E is autistic, but he respects the fact that he has the diagnosis and he wants us to everything we do. He never stood in the way of me doing anything, to going in any appointment and would never hold it against me.”

Effect on Social Life

Jack did not think his social life has been affected by the diagnosis. If he chooses to spend more time with his children is something that he always thought he would be doing once he became a father. Jack also, confessed that his children are far more important than “friends”. “We sort of don’t care being around people who don’t want to be around us and it kinda stops right there. If somebody has a problem with our kid because he is mildly something then they can leave, that’s kind of what it is.” According to Jack, to this day he has never been put to such a situation.

Even though Jack seems to not want to be surrounded by people who do not understand E’s behaviors, he does feel somewhat conscious of what other people may think of E. He described how during a family dinner at a restaurant one night, Jack and his wife noticed a couple sitting next to them staring at them and at their son. At the end
of their dinner, Jack walked up to the couple and apologized if for any reason his son’s behavior had disturbed their dinner. The couple appeared puzzled and said nothing back.

In retrospect, “sometimes I read into people. I think that they are thinking things that they are not. With everything that our son does it’s so difficult for us because it’s our older kid and because we don’t know if what he’s doing is odd because it’s odd or it’s odd because he’s autistic. So, we are always erring to the part of we better watch that and that keeps us on our toes and I don’t know if we always have to be on our toes.”

Experience Getting Services

In regards to getting services for E, Jack credits his wife Susan. According to Jack, Susan has been E’s best advocate since the very beginning and she has been striving to find the best services for their son. He confessed during the interview how he admires his wife’s continuous efforts to educate herself in order to be a better advocate for E.

Experience with Professionals

While talking about the professionals that have come across their life, Jack got passionate and fired up “there are people out there who are held out as experts and hold themselves out as experts, who, I believe, based on our experience, should not be held as such. I think that they are dangerous and that they perpetuate bad information.” Jack appeared bitter and hurt as some of those professionals did not rise to the occasion and let his family down, especially during the beginning of the diagnosis process.

Jack credited his wife for having such wonderful professionals presently working with E. “That is because Susan’s being fiercely protective, that also is reflective on the
way she deals with all the professionals that interact with E. If something is not going well she will remove him from that situation.”

Specifically, while recalling experiences with certain professionals “there have been certain therapists who have been fine but not for E, so they were gone. I’d rather, Susan in particularly, have nobody than have the wrong person. It’s our kid. This early intervention is only early for a short period of time, so we don’t have time to be polite right now for these things. We will be polite and respectful but if it’s not working, sorry, there are other people who need you. Go to them.”

**Hopes, Expectations and Fears**

“The first time I held E in my hands, I had fear and the day I received the diagnosis I had fear”. Jack was surprised to realize that he has had feelings of fear for E all these years. He tried to explain how his fear of holding his newborn son was different than the fear he felt when he was informed of the diagnosis, but in the end he recognized that fear is fear, regardless of what triggered it.

Nevertheless, Jack is optimistic and hopeful about E’s future. He has seen progress in his son’s development and he credited it partly to all the professionals working with him (“all the benefits of services seemed to have helped”), but mostly to his wife’s determination.

During the interview, Jack admitted that “I would never say the word autistic in front of E. I don’t think he knows what it means and I don’t want him to identify himself as being autistic. When he loses his diagnosis in ten years, I don’t know, and he can
understand what it is. I don’t know how I’d explain it to him because I don’t have the words for it."

Comparison and Contrast of Findings

Diagnosis

It appears as if the diagnosis of autism followed a process for all four families. Initially, there were simply some concerns, mostly language based, which eventually, after a series of events, led to a diagnosis. All four families were aware of their children’s developmental delays but uncertain about the extent of the delays. The news of the diagnosis was met by most of these families with feelings of both relief and sadness. It was interesting comparing the mothers’ reactions to the diagnosis to the fathers’ reactions, as for the most part they were similar, but, the fathers’ initial reactions included an attitude of determination and perseverance towards the future.

Effects on the Family

When extended family’s reactions were discussed with these parents the responses received were initially different. Cathy talked about being estranged from both the couple’s families, while Peter’s family was understanding but unable to provide support because of the physical distance between them. Susan and Jack reported how at first, they chose to keep their distance from their families. Nevertheless, all the parents interviewed reported that after a while relationships mended and grew stronger, and families were once again united.
Effects on Career

Every parent interviewed is college educated and their degrees vary from law to marriage and family therapy, to public administration. Both the fathers are the main providers in their households and are responsible for all finances. Both Jack and Peter reported cutting down their work hours upon receiving the diagnosis. Although, both Susan and Cathy have a college degree, they reported that the responsibilities of having a child with special needs do not allow them the time to work outside the home. Susan used to work prior to having her first born, but from the very beginning it was her wish to not work when they would have children. On the other hand, Cathy expressed that she had never really worked and even though she had once considered the possibility when her son was diagnosed she was certain that getting a job was not an option.

Effects on Social Life

All the parents interviewed explained that having a child with special needs brings changes to one’s social life. Nevertheless, all families admitted that the changes brought to their social life were voluntarily imposed and most of these families prefer to spend quality time with their nuclear family rather than with friends. Both Cathy and Susan reported that networking with other families with children with autism has provided a close social circle of support and trust. They both agreed that it has been easiest to relate to other families with children with special needs.

The fathers interviewed for this research did not seem to be concerned about the direction their social life may be taking. Their main priority was their family and they did not report the same need for relatedness as the women of this study. The fathers stated
that they were content without having any friends. The mothers on the other hand, even though they were comfortable with a smaller social circle of friends, they admitted missing the "luxury" of spending time with friends, dining or shopping.

Experience Getting Services

When parents talked about accessing services for their children, they all reported how overwhelming of an experience it was. All parents mentioned that at first, it was really difficult to advocate for their children as they did not know what services were available to them. Therefore, parents educated themselves in regards to the system and started to push both the Regional Center and the school district for much needed services.

Accessing services was described by all parents as a time consuming experience. A lot of waiting was involved, but as parents were determined to get services for their children, they pressed on until they finally got what they needed.

Another common theme that was revealed from the interviews was the difficulty transitioning from the Regional Center to the school district. Parents reported that during the transition they had to fight hard with both agencies to keep their services. The Regional Center was asking parents to request services from the school district, whereas the school district was communicating to the parents that they can only access certain services through the Regional Center.

Experience with Professionals

Overall, the parents' experience with professionals was described as positive. Along their journey of accessing services and interacting with professionals, all parents
had a story or two that was unpleasant. Out of the four parents it was only Cathy who reported a mostly unsatisfactory experience with professionals. The rest of the parents, even though they have had their share of disappointing experiences with professionals, they reported that they are now, fortunate to have a great relationship with all the professionals involved in their child's treatment plan. Peter, the single father, expressed how he considers at least a couple of the professionals he has been working with as good friends.

**Hopes, Fears and Expectations**

What all four parents have in common in respect to their children's future is concern. They appeared as if they are not as anxious as when they first received the diagnosis. They grew to be more at ease with their child's special needs and are only concerned about their overall happiness and well fare. All parents try to concentrate on the present and take the daily challenges as they come, instead of worrying about the distant future.

Regression is a common worry amongst these parents but was not much discussed during the interviews. It was almost as if the parents did not want to allow themselves to think of that possibility for more than what they have to. It's a possibility that needs not be thoroughly discussed with these parents.

Concerns about being financially and physically able to care for their children were also shared among the four parents.
CHAPTER 5: DISCUSSION

Summary

In light of the rise of autism rates the last decade, many researchers have been trying to investigate the disorder of autism. Much of the research has been focusing on causes and treatment approaches. However, as is the case with every childhood disorder or syndrome, when a child is affected by an illness or a disorder, the whole family is affected too. This present research aimed to investigate the effects of an autism spectrum disorder diagnosis on the family as a whole. More specifically, this research examined the effects of autism across seven categories.

These categories included: 1) parents' experiences of the diagnosis; 2) the effect of the diagnosis on the family; 3) effects on parents' career(s); 4) effects on parents' social life; 5) parents' experience getting services; 6) experience with professionals and, last; 7) hopes, expectations and fears.

For the purpose of this research four parents (n=4) were interviewed. Findings from the interviews indicate that a diagnosis of autism affects a family's life in various degrees, in the above mentioned categories. The findings also support past research that compares the parents' reactions to the emotional responses associated with Kubler-Ross's Stages of Grieving.

Discussion

Researchers have compared the emotions and feelings relating to receiving a diagnosis of autism to Kubler-Ross's Stages of Grieving. Those stages include: Shock, Denial, Sadness/Anger, and lastly, Acceptance and Adaptation. (Drotar et al, 1975, Gart,
1985, Blacher, 1984). Findings from this research partially support the Stages of Grieving theory. Almost all families interviewed were noticed to go through the last two stages; sadness/anger and acceptance/adaptation. However, these particular parents did not mention any reactions resembling shock or denial. On the contrary, all four parents expressed how they were concerned about their children’s development prior to the diagnosis. Some parents even expressed relief at the news of the diagnosis.

Featherstone (1980) discussed how parents never reach an absolute stage of acceptance. Searls (1978), a father of child with special needs himself, supported Featherstone’s beliefs. Searls reported that he never went through the stages the researchers suggest and that carrying negative feelings is part of parents’ emotional lives. In this study, the parents expressed several positive feelings about the diagnosis, which is the path that leads to acceptance, but at the same time, there were moments when parents’ negative feelings surfaced. For example, when Cathy discussed her son’s future, her negative feelings about the diagnosis were apparent. She fears for her son’s aggression and escalating behaviors, she fears for her younger children’s safety.

Even though De Myer (1979) reported that a diagnosis of autism intensely affects marital relationships, the parents of the present study stated that their marriages were stable. Cathy, Susan and Jack, all credited their spouses for being supportive and understanding throughout the process of getting a diagnosis. The only divorced parent interviewed reported that his divorce was not the result of the diagnosis of autism.

Culbertson (1977) studied parents’ reactions to a diagnosis of autism and establishing a treatment plan. In Culbertson’s study, parents described the process of receiving a diagnosis and establishing a treatment plan as a depressing process. Even
though the parents of this study did not use the exact same term for describing the process, their overall feelings included frustration, anxiety and in some occasions disappointment too.

In a study investigating a diagnosis of autism and stress, Gray (2003) reported that the stress of raising a child with autism has an effect on the mothers’ career choices. More specifically, choices of being employed, career advancement and promotion were all affected. In this study both mothers interviewed had chosen to not work but nonetheless, the reason behind that decision was not entirely because of autism. One of the mothers, even though she was highly educated, she had never worked before so there were she had no career choices affected by autism there. The second mother had a career prior to her son’s birth but it was not because of her son’s diagnosis that she decided to be a stay-at-home mother. The couple had agreed from the very beginning that once they had children, the mother would quit her job, as it would mean a lot to them for her to be with them, at least for the first three to four years. The same mother expressed that in her “plan” she should be getting back to work sometime soon, but a son with a diagnosis of autism and a three-year-old daughter are somehow putting her career on hold.

In regards to the effect of autism on sibling relationships, research findings are inconsistent and conflicting. Some studies support that sibling relationships are negatively impacted by autism, causing rivalry and jealousy between the child with autism and his/her non-autistic siblings (Rivers & Stoneman, 2003). On the other hand, researchers argue that siblings of children with autism are more likely to view their sibling relationship positively (Bagenholm & Gilberg, 1991). Even though no siblings were interviewed for this study, as per parents’ report, the sibling relationships seem to be
intact. Susan and Jack reported how E’s little sister acts very protective of her brother when they are around large groups of people. However, Cathy sadly reported that S does not seem to be attached to his baby twin siblings.

Lastly, past research revealed that grandparents go through the same stages of dealing with the diagnosis as the parents. Again, no grandparents were directly interviewed but the parents were able to report on the reactions of the grandparents when they received the diagnosis. Parents reported different reactions; Cathy’s parents were initially unsupportive; Susan and Jack chose not to include their parents in the initial process of dealing with the diagnosis, while Peter reported his parents being extremely supportive from the very beginning. Even though all families reported different reactions from the grandparents’ perspective, in the end grandparents were included in the family and are again active members of the family.

**Implications**

All research investigating the diagnosis of autism and families reactions has focused on comparing those reactions to the stages of grieving and loss. Indubitably, there are similarities between the stages of grieving and the reactions to the diagnosis of autism. Nevertheless, research should equally focus on the differences between the two.

An important piece, often overlooked, in the research is the severity of loss in each case. In the theory of loss and grieving, the loss is permanent and irreversible, whereas the diagnosis of autism is associated with a loss of the imagined, normal child. Upon receiving the diagnosis parents mourn the expected child-to-be and then find ways to move on. All the parents interviewed agreed that the diagnosis brought them a sense of
relief and armed them with the strength to fight for their children (get services, find professionals, etc).

Another point frequently neglected is the role of the fathers in the diagnosis of autism. Professionals are used to interact with the mothers, not really including the fathers in the team meetings. As we previously mentioned the fathers in this study, were both noted to be extremely involved in their child’s treatment plan but in different ways than the mothers. It appears as the fathers take over the financial responsibilities and try to provide for their families. That often requires that they work long hours not being able to escort their children in therapy sessions or attend meetings. The absence of fathers from treatment sessions and treatment plan meetings should not be perceived as a lack of interest from the fathers’ side. On the contrary, fathers seem to want to be more involved and possibly they could if the treatment team would only make arrangements to accommodate the fathers too in any decision making meeting.

The fathers interviewed for this study are both fortunate enough to have a job that allows them the flexibility to miss a few hours of work in order to attend an IEP or an IFSP meeting. However, the question raised is whether that's a luxury available to all fathers with children with special needs. A father of lower socio-economic status is very likely that would not be able to take a paid day off to attend such meetings. Since an unpaid day off would immediately jeopardize the family’s finances the father would decide to not attend the team meeting. Therefore, professionals should be mindful of each family’s needs and try to accommodate to the best they can both the mothers’ and the fathers’ needs.
Reviewing the findings of the current study, an interesting observation was that two of the children with autism were *in vitro* babies. While the present study’s sample is rather low to draw any conclusions between the *in vitro* pregnancies and the prevalence of autism, it should however be considered as a topic for future research. If for any reason there is indeed a relationship between the two, then possibly, in vitro procedures need to be readdressed and redefined. And families considering these procedures need to be informed.
REFERENCES


Appendix A

Dear Parents,

My name is Mairi Tsiftsi and I am a graduate student at California State University, Northridge. As part of my master's program in Educational Psychology I am preparing a graduate thesis.

For the purpose of my thesis study, I have chosen to explore parents' reactions to their child's diagnosis of an autistic spectrum disorder (ASD).

I am hoping my thesis will bring to light the delicate process of parents' response to their child's diagnosis. I am interested in learning about parents' thoughts and reactions and the impact of the diagnosis on their lives over time. Your experiences can assist me to learn ways to help other families in the same situations in the future.

In order to carry out my study, I would greatly appreciate it if you could take the time to complete the attached questionnaire. The questionnaire consists of 29 statements describing parents' reactions to the diagnosis.

If you wish you may withdraw from this study at any time.

I assure you that your responses will be treated with total confidentiality. You may choose not to answer any questions you don't feel comfortable with.

If, at any point of this research, you feel that you would like to seek professional counseling, please contact Nikki McRory, Clinical Director at 818-501-8352.

In case you have any questions regarding the study or the questionnaire, please feel free to contact me at 818-717-8374. If you have specific questions about the study, you may contact Dr. Jan Fish, faculty advisor, at 818-677-7891, janet.fish@csun.edu.

Thanking you in advance

Ms. Mairi Tsiftsi

65
Please indicate your willingness to participate in this study by checking this box ☐

☐ I agree to participate in this study.

Please fill in the details and circle the most appropriate response(s):

Sex of your diagnosed child: Male Female

Age of your diagnosed child:

Age of child at diagnosis:

Race: White Hispanic Asian African/American Other

Survey completed by: Mother Father Both Other (please describe your relationship to the child)
REACTIONS TO THE DIAGNOSIS OF AUTISTIC SPECTRUM DISORDER

The following 28 statements describe a range of parent responses to a child’s diagnosis of an autistic spectrum disorder. Indicate how much you agree or disagree with each statement by circling the most accurate response on the scale for each item.

1. I was upset that my child was not diagnosed earlier.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

2. I/We feel we are in a battle with time.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

3. I have mourned my “lost child”- the child without disabilities that I expected to have originally.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

4. The diagnosis helped me stop blaming myself.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

5. Since the diagnosis, my/our marriage remains stable.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

6. The diagnosis allowed me to set my expectations more appropriately for my child’s development.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

7. Since the diagnosis, I have become more worried about my child’s future.

   STRONGLY AGREE 
   AGREE 
   UNDECIDED 
   DISAGREE 
   STRONGLY DISAGREE

Please continue to next page
8. I was shocked/upset/devastated

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9. The diagnosis came at the right time.

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10. I felt the diagnosis was accurate.

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11. The future looks much better after the diagnosis.

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12. I feel guilty about my child's condition.

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13. Since the diagnosis, I have been able to accept my child's behavior.

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14. Getting the right services for my child has been an overwhelming and challenging experience.

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15. Our other child(ren) has/have been supportive/understanding.

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16. Since the diagnosis, I have treated my child like a "normal" child.

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17. The diagnosis has allowed me to raise my expectations of my child.

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18. My spouse and I, have had marital problems because of our child’s diagnosis.

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19. Our other child(ren) feel neglected.

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20. Nobody understands our situation with our child.

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21. Since the diagnosis, it has been easier to access professional services for my child.

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22. I still find it hard to comprehend my child’s behavior.

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23. The diagnosis brought me a sense of relief and hope

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24. I had a feeling my child had been misdiagnosed.

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25. I have mourned my “lost child”- the child without disabilities that I expected to have originally.

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26. Professionals have been very helpful and understanding.

STRONGLY AGREE  AGREE  UNDECIDED  DISAGREE  STRONGLY DISAGREE

27. I/We are just taking one day at a time.

STRONGLY AGREE  AGREE  UNDECIDED  DISAGREE  STRONGLY DISAGREE

28. The diagnosis helped me become stronger.

STRONGLY AGREE  AGREE  UNDECIDED  DISAGREE  STRONGLY DISAGREE

Please continue to next page
You can use this page, if you wish, to describe your feelings, thoughts or comments in your own words, regarding the impact of your child’s diagnosis on your life.

Thank you for your time!

Your response will contribute to improved services for children and families.
Appendix B

Interview Protocol

1) How has it been raising a child with autism? Challenges?

2) How has the diagnosis affected your life?
   i. career
   ii. social life
   iii. family

3) Describe your experiences with professionals

4) Describe your experiences in regards to accessing services for your child

5) What are your expectations of your child?

6) What does your child’s future look like?

7) What are your expectations of your child?
Appendix C

Case I: Cathy and S

Personal Descriptions

Mom child development background.
Dad in the trophy manufacturing business. Business owner.

Child: 8yrs, in vitro, first born, he was an easy child, taking the world in

Diagnosis

Help group 3 yrs horrible experience
5yrs official
18mos pediatrician concern for language- pediatric neurologist hypotonia- apraxia-oed
School district DD to get services at age 3
Mom concerns 3mos: premature
Really smart, sweet but can be very aggressive, good reader.

"there is zero doubt that he is autistic" —new neuro-psychiatrist

"To me it was almost a relief....because I didn’t have to walk around saying to my husband all the time J has autism. There is something wrong with J."

Family

I was estranged from most of my family until J got his diagnosis at the age of 5. L’s family was of no support whatsoever. I remember L’s father saying that J’s problems were the result of poor parenting.

I have found a lot of support from other friends who have kids with autism. Friends become our chosen family and that’s my philosophy in life. I’ve basically found my own support.

Married for 18 years. I think we have weathered a lot of storms (miscarriages, infertility and other things) before doing autism. I think if we had we not weathered all those things we would not be here because it’s too stressful. The daily stress of autism is too much. (the meltdowns, the planning, the aggression, the screaming, the constant supervision).

There is always planning around J.

73
J has adopted grandparents because I told you the rest of the family was lacking so when J was 6 wks old we met them at our temple. We used to go out every Friday night and from then on they took just J in. Every single Wednesday before J started school we’d meet for lunch. They had their little routine, they had their happy time.

You spent so much time dealing with the daily challenges that you don’t get to enjoy your child

Career

Stay at home mom with a child development background. MFT. Have never worked.

There have been times after having J that I would have thought of going back to work but then I thought there is no way. Who is going to run this place? I need to stay on top of what’s going on. I wouldn’t have known the things that were going on to the school unless I went there all the time to observe.

That’s another thing I forgot to mention: Money. You take everything there is from RC which is nothing, or you have to pay exuberant amount of money to get anything

Social Life

“...A lot of our time is spent doing therapy, making accommodations for J. there are a lot of things that we can’t do. Every decision is based on Can J handle it?...”

When he was younger, before he got too violent we used to go on vacation we went to Hawaii, we’d go to temple every Friday night but as he got older and bigger and louder we have to give more thought can we do this can we do that.

Experience getting services

3mos of waiting. A friend suggested she called the regional center. Speech and OT.

3yrs services stopped through RC. Typical classroom with 1:1 for a year and half. Went through mediation. He got services and diagnosis from SD. Get services from RC but RC didn’t give any.
Experience with professionals

“She just didn’t want to diagnose him with autism and I know now that that particular doctor doesn’t like to diagnose children with autism”

I wouldn’t say I’ve had a good experience with professionals. Everyone has a different suggestion for me. It’s very hard to get people to be part of a team.

I’d like to have a team approach. I am the team.

Hopes and expectations

I’d like to see J continue to make forward progress. I don’t see at this point J being able to live independently. I think that puberty is going to tell another story for J. Puberty seems to be the time when they can go one way or another.

I would like to see J live independently. Whether I believe that would happen I don’t know.

Fears: 1 that he will live with me for the rest of his life which is just not going to happen 2 as he gets bigger and he continues to be aggressive that he will hurt or hurt his brother and sister and that he’ll have to be placed in a residential placement because I won’t be able to manage him.

J. has a garden variety of autism:
Appendix D

Case II: Peter and L

Personal Descriptions

Father 44 divorced. Business owner.  
Mother didn’t show much interest in child’s progress.  
Concerns of child exposed to somewhat anger and violent environment at mom’s house.

Diagnosis

2yrs old -fancy Jewish school- your child has speech delays he doesn’t speak properly  
At that point no one was speaking about autism.  
At 18mos-3yrs he started speech therapy. At the age of 4 things started to fall into place.

Psychologist- Ariel 3yrs: “I’ve seen a lot of children of divorced parents and this is not the case. This is not the case of a divorce and not the case of environmental delay there is more than that”

Dad thinks older half brother has autistic tendencies.

I think I was relieved...because at that point the first month I met with the doctor. This is it, this is what you have to deal with and then I knew what I had to deal with, now I know what to do.

The way that I dealt with it was straight head on, teeth and nails. Everything that could improve his life was done (second opinions, ST, psychologists).

Family

Big family. Oldest sibling of 4. Very supportive grandparents but live far away (Israel). They can only visit every now and then and they stay for a couple of weeks.

Not trying to find a girlfriend or a wife right now-need to focus with your life on the child.

Ariel has a half brother and the effect of an autistic child on another child is not very healthy. But his half brother is not typical developing.

A cousin who lived here is now moving back to Israel too, and that leaves me pretty much almost by myself.

My support system is not as good as I wish it was, but academically A is going to be ok and also socially he’s going to be ok. I can not complain. I actually have to compliment the school district and the RC. I think I have nothing but compliments for them. The
people that they are hiring, the professional people they find all around me to help me. (name) (name) God I’ve got two good friends that I would never have. I’m very lucky. In this case I’m very lucky.

Career
Financially, when he was born, this house was cleared and I was clear of any debt. Today I owe 470,000 dollars. Big part of it was the divorce that got super expensive. But the fact that I was a single father and the primary caregiver and I took the role of female and the male in his life actually deprived me from the ability to work.

With parents in town for a few weeks he has been able to maximize profits.

I am working but not as much as I could. With my parents I trust them completely, he is safe, so I can leave him with someone I trust. The only time that was left for me to work was when he was in day care.

I can always work. I can always make money, but A is going to be a little child only once.

Social Life
Everybody came to the court with written declarations but what was the reality was that I was taking him to school and I was doing all the things that I was doing and I was working and I was actually canceling my life for that.

I could not sit down and wait for someone else to take care of him that’s my only child and I had to take care of him.

Experience getting services
He got everything his son needed even if that meant paying out of pocket. When he got the diagnosis he demanded all services from RC and SD.

Why should I wait for the services to be given to me on the list? If I have already been approved what I should and that’s the difference between me and some other parents, I’m not sitting down. I should go right away to the agency hand them the IEP and tell them look I’m approved for 30 hours a week. Why don’t you already start the providing the services?

We don’t want to wait because it might take time (to receive services) and we don’t want to lose this time.

I have difficulty presenting myself. I have a thick accent and people might….When I went to look for S.T for A I was rejected flat out from any place that I went. I believe that the first reason was my accent. The other reason was that A was one week with me and one with his mother. Although they could have done that, if it was a little difficulty, they
wished to avoid it.

Agencies may have said no because of the scheduling.

Experience with professionals

I actually have to compliment the school district and the RC. I think I have nothing but compliments for them. The people that they are hiring, the professional people they find all around me to help me. (name) (name) God I’ve got two good friends that I would never have. I’m very lucky. In this case I’m very lucky.

Hopes and expectations/ Fears

A very great concern. I know that I’m 44 and I’ve got about a good 25-30 years to provide for this child. And I need by the time that I’m going to be gone I need to make a situation that this child who is going to be a grown up man is going fully prepared step on his two feet and deal with the world...He needs to be financial secure and be able to control his financial security and then before that he needs to have a proper profession to provide for himself and before that he has to actually acquire skills to help him make a living...

...that he’s not going to be taken care properly.

Taking one day at a time.

I hope that when he’s 28 he’ll be working on his doctorate degree.

I want him to walk into the kindergarten with his academics intact, in line. Let’s face it better students have better social status.

A lot of hard work

I like everything I do with A. Just to wake him up in the morning is a pleasure; Putting him on the bus, telling him that I love him, blowing him kisses and him catching them.

What you guys are doing is taking a human being making a difference in his life that otherwise would not have happened. You got a child that has a problem and he’s destined to certain path and what you’re doing you’re coming over and your intervention is creating a completely different path in his life and it’s actually making the difference between a homeless under the bridge and a man in Beverly hills. The difference between the man in Beverly Hills and the man under the bridge is not luck. Whoever thinks it’s luck is a full. The difference is that you and Madeleine are making. Without you many
families can not make this difference, many families don’t have the knowledge and the ability to do that and what you are doing is noble. What you are doing is something not many people can do. Maybe no else can do it but you.

-How has it made a difference?
Just the knowledge that people like that exist is making everybody’s life easier. It’s helping me relax and be relieved...that there are people like that, who I trust, and I consider competent, educated and can make a difference. Any person like that who is helping another child is another angel in the world and the difference you (Madeleine) made for me, without you I don’t think I’d have the energy or the strength to go do anything with A. It was one of the hardest things to have done.
Appendix E

Case III: Susan and E.

Personal Descriptions

<table>
<thead>
<tr>
<th>Mom (stay at home mom)</th>
<th>dad (attorney)</th>
<th>G- baby sister (2.7yrs)</th>
</tr>
</thead>
</table>

G: High functioning autism. 5 yrs old. Extremely outgoing, very friendly, loves people, he’s come along way. Typical classroom with aide.

Diagnosis

2yrs 4mos: we took him to ST- she suggested going to RC- he had minor to significant speech delay. G has always been mildly delayed. Never extremes.

RC sent assessor- she got to see the worst. We have worked to hard as a family to pull together whatever resources we could find to get him where he is now.

Autism “I thought it was a child banging his head against the wall, no language, no thing. I had no idea”

I went to thoughts of he’s not going to get married, he’s not get married. In my family that’s what you do. You go to college and if you want you get married, you have children, you have a family and you have a great career and you invest your money and you save. We have very high expectations because everyone in my family has done that. All just crashing down. All your dreams crashing, crashing down for your firstborn and we went through infertility treatments to get G so we worked truly hard to get him so that was very upsetting.

Day of Dx: She fought really hard to get the diagnosis. I swear if I hadn’t spoken up we would have gotten PDD, we would have gotten DD. We kind of talked her into giving us a diagnosis. I was highlighting all the negatives (hand flapping, toe walking, etc) and she was alright. But hearing her say it...It’s like I don’t know you’re fighting with someone and you say I don’t want to be your friend and they go alright and you just don’t want to hear that...you almost want them to say no, he’s ok. Even though I fought hard for her to hear me, and then we cried J and I just like tears in the parking lot, it was very upsetting to us. The whole week was just awful. But there was also some relief putting a name to what was going on, finally, and knowing that we were going to get services. I called my family, I called my friends.

Here you are a mom, highlighting all the bad things about your child, it’s a horrible place to be in. to look at all the bad all the negative all the deficits and not to look at the positives, but you are trying to convince family and friends that there is something wrong.
We don’t know what’s typical or not. When it’s your first you don’t know. There are a lot of things that G does that’s just typical kid stuff and I don’t know that. I think it’s weird.

I find it’s very difficult when you have a true high functioning child. We don’t fit in the spectrum disorder world really well, but we also don’t fit in the typical world.

We got the best of the worst. My story is really “cry me a river” when I go to my support group. We are really lucky.

Family

Dad, J: he has come a long way. He didn’t think G had anything. He didn’t think anything was wrong.

Mom always had an issue of overspending. With G it got worst but because of G she sought helped and joined a 12 step program.

“when we were diagnosed”

We have a nanny only so I can go to therapy and M can get her naps and she has someone to pay attention to her and she’s not living in the waiting rooms of these therapy places. I refuse to let that happen.

Some of my family, this was really hard for me…they said oh we thought something was up because we’ve never been able to connect with him and we didn’t know why. That really bothered me. I was really angry at them that they also thought there was something wrong.

My parents are not perfect but they were very supportive and very loving. At first, when we first found out, we didn’t want anybody to talk about it to us, we didn’t want to know. We didn’t want anyone’s opinions about it. We needed to process it on our own in isolation within our nuclear family.

On thoughts of having another child: J needs to be on board that if we have a special needs child no matter what they have, we love that child, and he doesn’t resent me and he doesn’t blame me for it.

Going to the fertility doctors the next day for tests-Autism doesn’t show up on the tests and if it did would G not be here? Probably not but that’s something I can’t go there in my head coz if I go there I’ll never…I can’t do that, because he wouldn’t be here. And he is so high functioning, he is fine.

When I see my daughter I’m constantly reminded of what G didn’t do. I’m constantly reminded of how he lives delayed. And that’s hard. I can’t do it by my self. I have to tell people about that.
Siblings: They are great together. They have so much fun together. She loves her brother. Every night she climbs up in his bed and gives him a kiss goodnight.

Career

I’m probably going to go back to school. I think I’m going to get a masters in social work and work with mothers of children who are high functioning.

Bachelors in public administration- did advertising and promotions and marketing, a really fun job. I stopped working when I had G which we always had planned to do. I was always going to be a stay at home mom for a while and then go back. When everything happened with G it’s a good thing I didn’t have to work. I’m very lucky that my husband has a job where I don’t have to work. I couldn’t work. I went to tons of therapy. That’s what I did, that was my full time job.

Social Life

I love support groups. Knowing I’m not alone, without the support of these amazing women, that was huge. That group really helped me

I just want to be a mom and meet people for coffee, go out for dinners with friends. We don’t have a lot of friends. We have friends, that we had before this and we’re still friends, but I can’t meet them. I’m gone, I’m in therapy and their problems to be honest are so trivial compared to all the problems I hear at the support group and my problems.

Autism dramatically changed my way of looking of life just as a person because it forced me to re prioritize everything in my life. It really changed my whole psychology make up if you will and it forced me to have healthier priorities. Maybe that’s what happens to people who almost die.

I have 60 people I can call if I get upset on this list from my 12 step program.

Experience getting services

I don’t even know what to see. It’s been difficult but we always got what we wanted. We got everything we ever wanted for G. Difficult because people were saying G doesn’t need anything. Horrible experience with advocate (assigned by SD) During the IEP all the professionals (OT, ST, and advocate) thought G didn’t need any services. Professional at the IEP said: “If G is autistic I’ll shoot myself”

The whole process was very scary and frightening to me.

I learned from the other mothers at the support group, I learned from the attorney that we eventually hired. Just picked it up here and there.

He has an aide, Oh my god I cried so hard when I realized he had to get an aide. I was so upset. That was hard. Realizing that he needed an aide at school still makes me tear up because I knew what that meant. It meant judgment from other mothers; it meant
judgment possibly from other children. It meant being isolated from other families. It meant that everybody would know our secret, everybody would know he’s different.

Experience with professionals

It’s about 60% him, 40% therapy... I see direct, I mean direct, results from therapy...I personally believe that the therapy gave him the jumpstart.

He’s very charming, very likeable and thank goodness, because there are kids that aren’t and then the therapists, you know what? They don’t help them as much, because they’re only people, they’re only human beings.

Cal State program-extremely unhappy. Went to CDI- and again it was not the right place for him. He was the best in the room and he didn’t need to be there. I kept leaving programs, I gave it a little bit of time.

Excellent pediatrician. Thank goodness we have a pediatrician whose wife runs a program for autistic kids. So, he gets it. He’s on a great page. He just kept on counting words.

Hopes and expectations/fears

I just hope he has a happy easy life. That’s it. I just want him to fit in as much as he can which I think he does more than some do anyway. I just want him to be happy. I don’t want him to have difficulties or pain or suffering.

I’m not so worried about regression any more. I’m afraid that he won’t be happy he won’t have an easy life that it will be hard for him. They’re not real fears, they are not real. I know he’ll learn pragmatics. He learned everything else why not this? I worry about kindergarten. I try not to worry about down the road to much so it’s kind of hard for me to answer that question. You know what? You have to live for today and there is a quote that I love “happily ever after is one day at a time”. There are two places you have no business living in, the future and the past. You have to live in the present.

How will I know he is really doing ok?
Appendix F

Case III: Jack and E.

Personal Descriptions

<table>
<thead>
<tr>
<th>Mom (stay at home mom) - dad (attorney) - G - baby sister (2.7yrs)</th>
</tr>
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<tbody>
<tr>
<td>G: High functioning autism. 5 yrs old. Extremely outgoing, very friendly, loves people, he’s come along way. Typical classroom with aide.</td>
</tr>
<tr>
<td>Eye crossing, toe walking, stretches/tenses his hands/fingers, obsesses over things (i.e. bad guys in Disney movies)</td>
</tr>
<tr>
<td>Very good at soccer, telling stories. He’s charming.</td>
</tr>
</tbody>
</table>

Diagnosis

It’s very difficult and rewarding raising a child with special needs.

When we decided to become parents we were very clear and in an agreement that we were going to have an amniocentesis done. We were going to make sure that our child would be free of things. If there was any Down Syndrome detected we were going to abort the child and we just wanted to start clean and E family has a friend who they have a down syndrome child and she’s now 28 and she’s great but these people their entire life has been focused on this daughter that’s not what we wanted. We took the precautions that we knew to take and so we had this baby boy and he’s great and cute and wonderful and then everything that he did was toward the slow end, towards the late side of normal. He was never out of the range of the normal.

When it came time for his second birthday our pediatrician said you know you may want to have him evaluated. Well we didn’t right away E. was pregnant and we ended up not doing it. I think it was at his 3rd birthday that we did it.

From there (RC) we got this diagnosis from of their therapists there. He had said he might be autistic but I don’t think this guy who first gave the diagnosis had ever met G. I think he had based everything on what E. had said.

We have this diagnosis now and I don’t have this devastation because his diagnosis is based on a man who has never met my son.

We decided we needed a second opinion. We took our son to a developmental pediatrician whom we trust and was well respected and she said that G does in fact some developmental delays based on what she’s seen although when she saw him she said to herself I don’t know why these people are here he’s fine and then she noticed some of his behaviors. She realized that there were some deficits there. And she then gave him the diagnosis but she wasn’t positive about the diagnosis and she told us this. She said part of the reason she gave us the diagnosis was because she realized there are some deficits and
G could benefit from the services that he would get by having the diagnosis. But she said come back in a year or two I won’t be surprised if he doesn’t have a diagnosis.

A long winded history of our learning of his diagnosis.

The first time we heard the news of the diagnosis I didn’t know what autism was or is. To me it meant bad. The word autism meant bad and trouble very very personally, to me it meant that I’d have to take care of this little person because that’s my job and I have no idea how to take care of him. I don’t know if I’m going to have the ability to do that. Emotionally or intellectually or financially anything I just didn’t know if I was going to be able to do it.

The only reason why I’m not breaking down now, a couple of years later, he’s amazing. He’s a great kid. All the benefits of services seemed to have helped.

There are certain deficits I can’t live with for him.

I want him to have a chance to be smart. The devastating part of the whole thing is that he might lose all these possibilities in life. The loss of possibility and potential. That was the sad part.

As it turns out it’s not all about me. I have a wife who is able to do this, much better in many respects than I can do it and there is this whole community.

There is this sense of secrecy, my wife says denial. I think E would say that I was in complete denial. I think I might have been in denial outwardly, but I knew what I knew in the inside but I wanted to be optimistic and I didn’t want everything to be negative. E, goes negative because I think that’s her motivator. If everything is going wrong she has to get to work and make it right. That’s what propels her to help G. I on the other hand, can’t sort of live that way because I wasn’t brought up that way, so it’s horrible. I wouldn’t want to wallow in this kind of defeat. For me the negative would be defeat and I don’t think I could work from there. If I see defeat I might give up so I can’t go there.

I would look at his positive attributes and she’ll look at his negatives.

Then there is a sense of secrecy, not shame coz I’m not ashamed of anything. I’m not ashamed of him. I wanted to keep it a secret because I didn’t want anybody to place any judgments on him.

As a result of this diagnosis I have become more patient with my son obviously and with other people. I look at people and say there are things we don’t know about people and I believe I much more patient. I have become a much better father, more attentive, more appreciative of successes. I still believe he can become anything that he wants to be because his expressive abilities I think that he’s showing to us and others that he’s really smart, he has great memory, he processes things differently but he gets it all and he wants
to do everything.

I would never say that word (autistic) in front of G. I don’t think he knows what it means and I don’t want him to identify himself as being autistic. When he loses his diagnosis in ten years, I don’t know and he can understand what it is. I don’t know how I’d explain it to him because I don’t have the words for it.

Family

Everybody has been great. We are incredibly lucky. My mother loves my kids, particularly G because he’s her first grandchild. She’s insanely devoted to him.

And now molly, there is such a connection there.

My father loves them and him. My stepmother is great. She is not the warmest person in the world but she’s trying.

E. had to explain to them some things in the beginning.

They are both treated the same. He is treated more than he is. More severely and harshly not because he is autistic but because he is older.

Career

I think I stay at work a little less. I happen to have a great boss. First of all, he never believed that G is autistic, but he respects the fact that he has the diagnosis and he wants us to do everything we do. He never stood in the way of me doing anything, to going in any appointment and would never hold it against me.

Social Life

I don’t think it has affected my social life. I think we’d be doing the same thing. Maybe we spent more time with our kids as a result of this. I think I always understood this. So, no I don’t think the diagnosis has affected our social life.

We sort of don’t care being around people who don’t want to be around us and it kinda stops right there. If somebody has a problem with our kid because he is mildly something then they can leave, that’s kind of what it is.

Sometimes I read into people. I think that they are thinking things that they are not. With everything that our son does it’s so difficult for us because it’s our older kid and because we don’t know if what he’s doing is odd is because it’s odd or it’s odd because he’s autistic. So, we are always airing to the part of we better watch that and that keeps us on
our toes and I don’t know if we always have to be on our toes.

Experience getting services

Experience with professionals

There are people out there who are held out as experts and hold their selves out as experts who I believe based on our experience should not be held out as such. I think that they are dangerous and that they perpetuate bad information.

Overall it’s been good. That is because E being fiercely protective that also is reflective on the way she deals with all the professionals that interact with G. If something is not going well she will remove him from that situation.

We had another professional who was incompetent to deal with us and so she was gone. There have been certain therapists who have been fine but not for G, so they were gone. I’d rather, E. in particularly, have nobody than have the wrong person. It’s our kid. This early intervention is only early for a short period of time, so we don’t have time to polite right now for these things. We will be polite and respectful but if it’s not working sorry, there are other people who need you. Go to them.

Hopes and expectations/fears

I think the future looks pretty good.

The first time I held G in my hands I had aspirations, not expectations. The first time I held him in my hands I had fear and the day I received the diagnosis I had fear.

I don’t know much about autism. I do know there is this incredibly large spectrum. So if somebody said to me their child has autism I wouldn’t know what they mean by it.
This Protocol Approval Form must be completed for all California State University, Northridge faculty and student research which involves human subjects. Additional material(s), as described below, must be attached to this form at the time it is submitted to the Standing Committee for the Protection of Human Subjects (SACPHS) in the Office of Research and Sponsored Projects (BR 265, ext. 2901). All signatures must be obtained prior to submission. Brief, excerpted definitions and guidelines regarding research involving human subjects appear on the attached instructions. For a copy of complete regulations, contact the Office of Research and Sponsored Projects. Read all instructions before completing the form.

PLEASE TYPE OR PRINT NEATLY

1. Title of research: Exploring parents' reactions to their child's diagnosis of an Autism Spectrum Disorder (ASD). 

2. Name of researcher(s): Mari Takiy. Campus: ext. Major or Educational Department: Psychology: Early Childhood Education.

3. Address: Home phone: Email Address: 

4. Period of Project (see pg 1-Itemized Instructions) From September, 2005 To December 2005.

5. Check one: Faculty Research Student thesis Other (specify) Course prefix and number: Course title: Thesis/Graduate Project

6. History of Protocol: New Annual Previous Approval Date: 

7. Does this protocol contain modifications from a previously approved protocol? Yes (explain) No

8. Does the protocol concisely describe the research and how the rights of the human subjects involved are to be protected from unreasonable risk? Yes No

9. Are copies of any questionnaire(s), survey instrument(s) and/or interview schedule(s) referred to in this protocol statement attached? Yes No

10. Is draft Informed Consent Form(s) attached? Yes No

11. Is a Subject Bill of Rights attached? Yes No

12. Are copies of any questionnaire(s), survey instrument(s) and/or interview schedule(s) referred to in this protocol statement attached? Yes No

13. Is draft Informed Consent Form(s) attached? Yes No

14. Is a letter of permission attached? Yes No

15. Is a letter of permission attached? Yes No

16. SIGNATURES: Refer to section 1- General Instructions, Table 1 before signing.

Chair, SACPHS or Director of Research Office Use Only:

Approved, expedited review

Approved, reasonable risk

Not approved

Date received:

Date received: