

A SURVEY OF PARENT SATISFACTION ABOUT
SERVICES FOR CHILDREN WITH PERVASIVE
DEVELOPMENTAL DISORDER

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DEVELOPMENTAL DISORDER

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TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION.....	1
II. REVIEW OF LITERATURE.....	4
Parent Stress.....	4
Diagnostic process and Parent stress	11
Post diagnosis experiences.....	17
Initial Reactions	18
Family Life.....	19
Geographical Location.....	20
Intervention and Parent stress	21
Effective Interventions.....	22
Models of Service Delivery	25
Limitations of Previous Literature	27
III. PURPOSE OF THE STUDY	29
Primary Purpose of the Study.....	29
Second Purpose of the Study: Descriptive Information.....	30
Third Purpose: Current Stress and Satisfaction with Current Services.....	30
Fourth Purpose: Possible Correlates of Stress at Diagnosis.....	31
Fifth Purpose: Possible Correlates of Geographical Location.....	31
Sixth Purpose: Correlates of Type of Diagnosis.....	32
Hypotheses.....	33
IV. METHODOLOGY	35
Participants	
Parent Characteristics.....	35
Child Characteristics.....	36
Measures	
Personal Information.....	37
Early Autism Experiences Survey	37
Parental Stress Scale	38
Perceived Stress Scale.....	39
Demographic Information.....	40
Procedure	40

V. RESULTS	43
Age of First Concerns, Referral, Diagnosis and Intervention.....	43
First Concerns.....	45
Initial Reactions.....	46
Referral, First Diagnosis and Second Opinion Diagnosis.....	46
Most Recent Diagnosis.....	49
Post Diagnosis Reactions, Thoughts and Coping Strategies.....	50
Post Diagnosis Help.....	51
Time Spent by Professional During the Feedback Session of Diagnosis.....	52
Intervention Services.....	53
Time and Money Spent in Diagnosis and Intervention.....	57
Geographical Location.....	57
Parent Stress.....	58
Satisfaction of services.....	58
Therapy Model Preferences.....	59
Current status of the Child.....	60
Current Stress and Satisfaction with Current Services.....	61
Possible Correlates of Parent Stress at Diagnosis.....	62
Geographical Location and Current Stress.....	64
Geographical Location and Satisfaction with Current Intervention Services.....	64
Type of Diagnosis and Parent Stress.....	65
Type of Diagnosis and Parent Satisfaction with Services.....	66
Exploratory analysis.....	67
VI. DISCUSSION.....	70
Ages of First Concerns, Referral, Diagnosis and Intervention.....	70
Parent Characteristics.....	71
Resources Spent on Diagnosis and Intervention.....	73
Issues of Assessment and Diagnosis.....	74
Parent Stress at Diagnosis.....	81
Parents' Perception About the Causes of Autism.....	84
Issues about Intervention.....	87
Time Spent by Professional.....	90
Current Stress.....	90
Parent Satisfaction.....	92
Geographical Location.....	93
Parent Preferences of Models of Therapy.....	94
Current Status of the Child.....	96
Strengths.....	96
Limitations and Weaknesses.....	98
Clinical Implications.....	99
Directions for Future Research.....	103
Summary	103
REFERENCES	105

TABLES.....	119
APPENDICES.....	135

LIST OF TABLES

Table	Page
1.....	119
2.....	120
3.....	121
4.....	122
5.....	123
6.....	124
7.....	125
8.....	126
9.....	127
10.....	128
11.....	129
12.....	130
13.....	131
14.....	132

CHAPTER I

INTRODUCTION

The *Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition, Text Revision* (DSM -IV-TR; American Psychiatric Association, 2000) classifies autistic disorder under an overarching categorization of Pervasive Developmental Disorders (PDD). It defines PDD as disorders that are characterized by severe and pervasive impairment in several areas of development including reciprocal social interaction skills, communication skills, and the presence of stereotyped behaviors, interests, or activities. According to the DSM- IV-TR, the PDD includes Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS). In the literature, it is not uncommon to see the term “autism spectrum disorders” being used interchangeably with “PDD.” For the rest of this paper, the term “autism” will be used to represent the autistic disorder.

Autism research has been gaining attention in the recent years, due to the increasing incidence of the disorder in the population. According to Frith (2003), recent epidemiological studies on autism suggest that the prevalence of autism is around 60 per 10,000 for the autism spectrum disorders with an estimate of between 8 and 30 per 10,000 for autism in its more classic form. This is a potentially large increase from the estimate of 4.5 per 10,000 obtained in the first epidemiological study of autism by Lotter (1966).

This demonstrates that the identified incidence of autism in the population is increasing. However, one of the most heated discussions in the area of autism is whether rates of incidence are actually rising, or if improved diagnostic techniques and increased awareness of the disorder amongst professionals account for the rises seen throughout the United States and Europe (Frith, 2003). In spite of the fact that the diagnostic and intervention techniques may have improved, parents of children with autism still face difficulties in the process of obtaining diagnosis resulting in delayed interventions (Nissenbaum, Tollefson & Reese, 2002). Research suggests that the longer the diagnosis is delayed, the longer children will have to wait before they are provided with suitable education and/or intervention (Howlin & Asgharian, 1999). Consequently, inappropriate education methods may be used in schools which may result in academic failures, which may in turn cause various emotional and behavioral problems. Thus, early diagnosis is a very important step in the treatment process of a child with autism.

Howlin and Moore (1997) conducted a survey of parents of children with autism in the United Kingdom to evaluate the length of delay experienced in acquiring a diagnosis. It was found that the average age at which diagnosis was received was 6 years. The current study sought to update the findings from the Howlin and Moore (1997) study by conducting a survey to examine the age at which diagnosis and intervention services are being received now.

Research suggests that initial diagnosis of any developmental disability evokes emotional stress in families (Poehlman, Clements, Abbeduto and Farsad, 2005). Parents play a vital role in their child's treatment program and thus, carry the responsibility of finding the best available services for their children. Some parents take on the task of

being their child's therapist, while others prefer therapist led service delivery for their child. Stress may be experienced during this process of being in one of these roles. This stress may stem mainly from issues such as obtaining diagnosis at an early age, accessibility (financial as well as locational) of intervention services, and managing family life. In order to make the diagnostic process less stressful, it is important to discuss issues leading to a satisfactory diagnostic and intervention process. Therefore, the proposed study investigated the role of stress and geographical location as possible individual correlates of the parent satisfaction with intervention services.

Chapter 2 presents a review of literature of autism diagnosis, intervention and related parent stress. The literature review starts with a discussion of the nature of stress experienced by parents of children with autism. This is followed by a discussion of need for early diagnosis and the age at which diagnosis is being received. Next, studies on early diagnosis and parent satisfaction with the diagnostic process are reviewed and implications for the current study are presented. Furthermore, a review of studies on parent reactions to a diagnosis of autism is presented. Subsequently, studies on parent satisfaction of intervention services are reviewed. Empirically supported interventions and models of service delivery are described briefly in the final section of the literature review. Subsequent chapters deal with the purpose of the current study, method, results and the discussion.

CHAPTER II

REVIEW OF LITERATURE

Parent Stress

Families of children with mental and physical disabilities face many challenges. Autism is considered to rank among the most stressful of the childhood developmental disorders (Gray, 2006). This stress may stem from a variety of issues such as the child's problem behavior, inaccessibility of necessary therapeutic services, and dependency of the child on the family, thus limiting family activities. Researchers have demonstrated that the emotional turmoil experienced by the caregivers of a child with autism can result in a variety of psychological problems including depression and anxiety (Bailey, Golden, Roberts & Ford, 2007; Bristol and Schopler, 1984; Hoppes and Harris, 1990). The results of Bailey et al., (2007) suggest that mothers of children with disabilities generally exhibited a higher than average rate of depressive symptoms and were more at risk for clinical depression. Furthermore, it was found that child behavior problems, maternal stress, coping style, and support were consistently associated with depressive symptoms (Bailey et al., 2007). In addition, it has been shown that high levels of stress experienced by mothers of children with autism are correlated with limited educational progress of their child (Robbins et al., 1991). Thus, the importance of recognizing stress in parents of children with autism needs to be emphasized.

Parent stress has been studied in relation to various disorders such as Down's syndrome and other developmental disabilities (Herman and Thompson, 1995; Krauss,

1993), pediatric chronic illness (Sheeran, Marvin, & Pianta, 1997), and pediatric cancer (Streisand, Kazak, & Tercyak, 2003). Even though parent stress is a relatively new topic in the field of autism; there have been studies that have looked at parent stress specifically with children with autism (Moes, Koegel, Schreibman & Loos, 1992; Noh, Dumas, Wolf & Fisman, 1989; Sanders & Morgan, 1997; and Yamada et al, 2007).

Noh and colleagues (1989) conducted a study to compare the levels of stress on several dimensions of parenting in mothers and fathers of children with conduct disorder, autism, Down's syndrome and no disabilities. The sample consisted of parents of 159 children (31 with autism, 31 with Down syndrome, 35 with conduct disorder, and 62 typically developing children). Parents completed the Parenting Stress Index (PSI) which yielded scores on two domains; the parent and the child characteristics. Comparisons in the levels of stress reported by parents were conducted using multiple regression analysis.

Results showed that there were no significant differences between the stress scores of parents in the normal group and the parents in the three diagnostic groups. However, the mothers of children with handicaps seemed to have more difficulties than mothers of normal children with respect to depression and sense of competence in their parenting role. There were also indications that the mothers of children with handicaps were more likely to feel the burden of childcare demands. As a result they are more likely to feel isolated. There were no significant differences among fathers of the normal group and the three diagnostic groups on the parent domain of the Parenting Stress Index.

On the child domain, both mothers and fathers of children with conduct disorder and autistic disorder reported elevated stress on most of the subscales of the Parenting Stress Index as compared to the control group. Thus it was evident that the parents of children

with conduct disorders or autism found the parenting role more difficult than the parents of normal children. Furthermore, the elevations on the adaptability, demandingness, and acceptability scales suggested that the stress experienced by parents of children with conduct disorder and autism stems from the children's rigidity with their social environment, parents' perception of the children as being less attractive, and children's behavior problems. As a result, it was found that these parents were at much greater risk of parenting stress than were parents of children with Down's syndrome and normal children. Additionally, results showed that mothers of all exceptional children were at greater risk than mothers of normal children on the Parent Domain as a whole indicating that they may not only experience their children as being the source of stress, but may also suffer personal dysfunction such as maternal depression, lack of competence, and feelings of poor health. On the parent domain, while it was evident that the depression subscale was significantly correlated with the maternal perception of stress, the competence subscale was found to be significantly correlated to stress in fathers. Overall, this study suggested that clinicians should consider mothers' as well as fathers' stress. Also, parenting stress experienced by mothers may be alleviated by improving their depressed mood, and the fathers' stress may be reduced by increasing their competence in the parenting role.

Another study supporting the results from Noh et al., (1989), was the Moes et al., (1992) study. This study compared the stress profiles of 18 mothers and 12 fathers of children with autism on three measures: the Questionnaire on Resources and Stress; the Coping Health Inventory for Parents; and the Beck Depression Inventory. The mean age of children in the study was 6 years (range = 3 to 14 years). Independent sample *t* tests

compared the mothers' and fathers' mean scores on each of the scales. Overall results indicated higher stress for mothers than fathers. Stress related to family and parent problems (as reflected by the scores on Questionnaire on Resources and Stress) suggested that mother's perceived greater stress for themselves, other family members, and the family as a whole in caring for the child with autism. Furthermore the results also showed that the mothers of children with autism in this sample were more likely to desire cooperation and optimism from others to reduce their stress. It is also noteworthy that the mean Beck Depression Inventory scores for mothers were nearly twice as high as that for fathers, suggesting that mothers of children with autism may be at a greater risk for experiencing depression than the fathers. Moes et al., (1992) suggested in this study that this pattern may have been due to the fact that primary caregivers perceive the child's shortcomings as their own failures resulting in depressive feelings. However, fathers can evaluate self-worth through careers and his contributions as the bread-winner for the family.

Thus, this study evaluated the differences between the natures of stress that mothers and fathers of children with autism experience in the parenting role. Moes and colleagues (1992) mentioned that these data were preliminary data suggesting further systematic research to confirm the results obtained in this study.

Sanders & Morgan (1997) examined stress and adjustment in parents of children with autistic disorder, Children with Down's syndrome, and typically developing children. A total of 54 families were recruited, with the age range of children being 7 through 11 years. The Peabody Picture Vocabulary Test (PPVT) was used to determine the mental age of children with autism and Down's syndrome. The short form of the

Questionnaire of Resources and Stress was used to measure stress experienced by families. General family adjustment was measured using the Family Environment Scale. The purpose of the study was to determine whether the groups (autistic disorder, Down's syndrome and typically developing children) differed from each other based on parent stress and general family adjustment. A Multivariate Analysis of Variance (MANOVA) was conducted for each of the measures. Results indicated that mothers and fathers of children with autistic disorder or Down's syndrome reported more stress in raising their children than did the parents of typically developing children, especially with regards to the time demands and family opportunity. Both mothers and fathers showed pessimism about the future of their children, especially about problems that may arise when they reach adulthood. Mothers of children with autistic disorder and those with Down's syndrome showed less family participation in recreational and sporting activities than did mothers of typically developing children. This suggests that families may have less time and energy to spend outside of their family environment due to two possible causes. It is possible that they are depressed and may no longer show pleasure in fun activities. Another possibility may be that parents find caring for a child with disabilities to be exhausting emotionally as well as physically. Even though they may want to reduce stress by engaging in leisure activities, they may not have the physical or emotional resources to do so.

Yamada et al., (2007) evaluated the emotional stress level of parents caring for children with autistic disorders or other Pervasive Developmental Disorders including Asperger's disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Parent characteristics such as personality and marital relationships were

examined as possible correlates of parent stress. They also explored child characteristics such as intelligence, clinical characteristics and behaviors as possible correlates of parent stress. They measured stress using the K6, which is a self-report questionnaire that taps into general psychological distress in the past 30 days. NEO Five-Factor Inventory was used to measure the personality characteristics of the parents. The Intimate Bond Measure was used to evaluate the nature of the marital relationship of the parents. The Wechsler Intelligence Scale for Children-Third Edition (WISC-III) was used to assess intelligence of the children. The developmental quotient was measured using the Kyoto Scale of Psychological Development. The Pervasive Developmental Disorder–Autism Society Japan Rating Scale was used to examine the characteristics of children with PDD. Finally, information regarding children’s schools such as problems with peers, their participation in school lessons, and the frequency of school attendance was obtained.

A stepwise multiple regression analysis of the stress scores of the mothers and fathers was conducted, with the child characteristics, husband–wife relationship, and personality traits serving as the independent variables. While higher stress levels were found among mothers of children with all subtypes of PDD, it was suggested that the stress levels were higher among the mothers than the fathers of children with PDD. These results are consistent with the previous studies (Noh et al., 1989; & Moes et al., 1992). The personality tendency of the parents specifically neuroticism was found to be most closely associated with the parents’ emotional stress levels. Dominative and intrusive attitudes of the father were significantly related to mothers’ stress scores.

It was also found that the children’s problems at school were associated with the mother’s emotional stress level. Furthermore, the child behavior and child’s clinical

characteristics were also associated with the emotional stress level of parents. None of the child's age, subtype of PDD, or intelligence or developmental quotients was correlated with the stress scores.

Overall, the studies described till now evaluated the correlates of stress (such as personality characteristics of parents, marital relationship, and family adjustment. While all the studies examine the differences in stress profiles of both mothers and fathers, only two studies (Sanders & Morgan, 1997; and Yamada et al, 2007) additionally describe the correlates of this stress in mothers and fathers for children with autism. Therefore the present study sought to explore other possible correlates of stress such as child's age at the diagnosis, geographical location, progress that the child has made till now, parent satisfaction with services received, and the level of difficulty obtaining these services.

Furthermore, it was noted in these studies that the children with Pervasive Developmental Disorders (PDD) were analyzed all together without differentiating their subtypes. There may be probably more ambiguities in the differential diagnosis when another PDD rather than autistic disorder is the target disorder. These ambiguities in the diagnosis may cause a delay in diagnosis, thus causing the parents to be more stressed. The present study sought to differentiate between the subtypes of the PDD and evaluate the differences in possible correlates of parent stress. Although all the studies have useful implications for interventions, the sample sizes were small. Therefore the current study sought a relatively larger sample. While previous studies included the child and parent characteristics as possible correlates of stress, they failed to include specific issues related to the diagnosis and treatment.

Diagnostic Process and Parent Stress

Early detection and screening of autism in young children as early as 18 months has been made possible (Baird et al., 2000; Robins, Fein, Barton, & Green, 2001). Recently numerous researchers (Lord, 1995; Stone et al., 1999; Cox et al, 1998) have demonstrated the accuracy of early diagnosis. Specifically these studies conducted initial diagnostic evaluation at 20-36 months and the subsequent evaluation at 45-50 months. Cox and colleagues (1998) found that all of the nine children clinically diagnosed to have autism at 20 months retained a diagnosis within the autism spectrum at 42 months, with six meeting DSM-IV criteria for autism, two for atypical autism, and one for other PDD. Thus the results suggested good stability of diagnoses over time. In spite of the fact that early diagnosis is now possible, delay in diagnosis may be caused by other factors such as lack of awareness about the disorder, delay in noticing first concerns, professionals' lack of expertise and difficulty accessing services.

There have been few studies which investigated parents' perceptions on how early the diagnosis is being received in spite of the improved diagnostic tools. One such study conducted by Smith, Chung and Vostanis (1994) examined the parents' early experiences with the diagnostic process in West Midlands, United Kingdom. Families of 167 participants ages 19 years and below participated by filling out a questionnaire. Results showed that in 87 % of the younger and 84% of the older group, it was the parents who were first concerned about their child. The first signs parents noticed were speech delay, unresponsiveness to others, and lack of imaginative play. There was no difference in the first signs of concern that were reported by either of the groups. While the younger group parents reported seeking help for the first time from health visitors and

general practitioners, older group parents reported seeking help for the first time from a greater variety of professionals including social workers and nurses, in addition to the health visitors and general practitioners. The time between visiting the professional and seeking a referral for the younger group parents was half that of the older group. The majority of the participants received a single diagnosis, but a few were given a dual diagnosis of mental retardation and autistic tendencies. The mean age at which the children received a diagnosis of autism or autistic tendencies differed by group with younger receiving diagnosis at 43.5 months (i.e., 3 years, 7 months) and older at 82.7 months (i.e., 6 years, 10 months). Only a small proportion of parents were satisfied with the services and help received after diagnosis. They reported being dissatisfied specifically for not receiving appropriate special education programs at schools even after receiving the diagnosis and recommendations from a multidisciplinary assessment performed by the school. The results of this survey indicated that even though the children in the younger age group were being diagnosed at earlier ages, parents still faced difficulties in obtaining initial advice and support needed following the diagnosis. An additional concern mentioned by parents was that of misdiagnosis from some professionals.

Howlin and Moore (1997), expanded on the Smith et al., (1994) study by providing a more comprehensive survey. They collected data on the age at which parents first became concerned; reasons for the early concerns; age at which help was sought; professionals seen; final diagnosis obtained; general satisfaction with the diagnostic process and the intervention services received after diagnosis was made; time taken from the referral to obtain diagnosis and the professionals involved. Parents were contacted via local support

groups and autism societies. It is noteworthy that this study was conducted with over 1200 participants falling in the age range of 2-49 years from all over the United Kingdom.

The average age at which the diagnosis was received was 6 years, which the authors reported as being earlier than before. This indicates that the parents had to wait until 6 years of age to receive a diagnosis and then subsequent intervention services. However, according to Smith et al., (1994), the diagnosis was being received at the mean age of 3 years, 7 months for younger group children (1-9 years) and 6 years, 10 months for older age group (10-20 years). Parents also found the diagnosis of autism or Asperger's more satisfactory than simply a vague description of their children's traits. Satisfaction with the diagnostic process was found to be dependent on the length of time parents had to wait before receiving the diagnosis. Other factors found to be related to parental satisfaction with the diagnostic processes were the geographical area where diagnosis was received, child's age at diagnosis, delay between first seeking help and confirmation of diagnosis, child's current age, and the final diagnosis given.

Using data obtained from the Howlin and Moore (1997) study, Howlin and Asgharian (1999), conducted another study to examine whether there are differences between experiences of parents who had received a diagnosis of Asperger's syndrome for their child and those who had been diagnosed with autism. Parents of children with a diagnosis of autism were first concerned about their child's behavior by 18 months as opposed to 30 months for the parents of children with Asperger's. Parents in the Asperger's group reported being self assured that their children would grow out of their symptoms and thus were not worried. This led the parents of children with Asperger's

syndrome to experience more frustration and greater delays in their search for a diagnosis than those with children with autism. The average age when the diagnosis was confirmed was 5.5 years for the autism group and 11 years in the Asperger's group. Fewer than 10% of parents in either group received a diagnosis at the first consultation and around half were referred for a second opinion. Due to the unclear nature of the diagnosis given, many parents were reassured that there was no problem. A substantial majority of both groups went on to seek a further consultation. Forty-four percent of the autism group and 33% of the Asperger's group received a diagnosis at the second consultation. Other parents were referred further for a third consultation, at which 60% or more families in either groups received a diagnosis. More parents in Asperger's group were told not to worry at the third consultation, when their child was over 9 years old on average. The study found that the distribution of the diagnoses, i.e. the distribution of frequencies of cases having autism or Asperger's diagnosis, varied from region to region. However the overall ratio of children with autism to children with Asperger's was 4:1. Finally, it was also revealed that the parents of children with Asperger's syndrome were less satisfied with the diagnostic process than those with children with autism. There was also a significant correlation between the length of time required to obtain a final diagnosis and the parent satisfaction.

In addition to studies involving satisfaction of parents of children with autism, there have been studies involving parents of children with special needs in general. Stallard and Lenton (1992) conducted a consumer survey with parents of 41 pre-school children with special needs to determine their satisfaction with the services they had received and how

these could be improved. The participants consisted of children with special needs in the age range of 19-71 months.

The results indicated that the parents reported a high level of satisfaction overall. However, 29% reported that they did not feel they had received adequate information regarding the resources available, 61% reported that they did not feel they had received adequate information regarding financial benefits available, 54% reported that they did not feel they had received any advice on the availability of respite cares and 61% reported that they did not have the opportunity to discuss their child's future and the prognosis. As was true with the previous studies (Howlin and Moore, 1997; Smith, et al., 1994), it was clear that in most cases parents were the first individuals to be concerned about their child's condition. Parents also reported that they would like to be treated as partners in the treatment process and would appreciate an establishment of a link-worker who could act as a case manager. Hence collaboration of parents with professionals was reported as being essential in coordinating services which may help in reducing the stress experienced during this process (Moes, 1995).

Examining the qualitative data for important themes resulted in the following needs identified by parents: the need for more information provided to the parents regarding the resources available, the need to consider parents' emotional status rather than only focusing on the child's symptoms, and the need to treat parents as partners in their child's treatment process. Thus, the interview conducted in this study gathered information on various issues related to the satisfaction of the treatment process, such as, information regarding the prognosis of the child and available resources, and parent expectations of treatment. These issues were taken into consideration while designing the current survey.

In addition to parent satisfaction, one study explored professional opinions regarding the diagnostic process (Nissenbaum, Tollefson and Reese, 2002). They examined parents' as well as professionals' views regarding the interpretive conference in which the parents are informed of their child's diagnosis. Twenty-eight participants; 11 professionals who had diagnosed autism and 17 parents of children with autism, were interviewed.

They found that the professionals still think of autism as a controversial disability with some social stigma attached to it. Parents described it as a "death sentence" or a "lifelong sentence." Some parents described all children with autism as being similar to the character in the movie "Rain Man." While most of the parents described positive outcomes for their children, many professionals endorsed negative outcomes such as mentioning that they would be devastated if their child would have been diagnosed with autism. Additionally, professionals described autism as a lifelong disability with no cure; however they endorsed the fact that positive outcomes might be likely if early intervention is implemented. Before presenting the diagnosis to the family, professionals reported planning the session and preparing an information packet consisting of administrative paperwork, drawn visual aides, assessment reports, and recommendations. They also stated that they use reflective listening and simple language while presenting the diagnosis to the parents. Professionals mentioned that they educated the families about how autism differs from other diagnoses. Professionals reported that they attempted to understand parent's feelings and thoughts about the diagnosis. While many professionals indicated prognosis as difficult to speculate, a few suggested appropriate

interventions which might help improve the prognosis. In the area of interventions, only one professional reported discussing various treatment options.

Most of the parents in the study indicated a positive experience during the interpretive conference. Most parents recalled that the professional exhibited positive nonverbal communication such as good listening, empathy, compassion and genuine interest in the child's well being. Some parents indicated that they felt uncomfortable due to the inappropriate body language of the professionals conveying lack of interest. Some parents recalled that the professional provided opportunities for asking questions. While some parents reported that recommendations were not offered, many reported that recommendations were discussed. Most parents thought that they should have received more specific information regarding the interventions rather than broad recommendations. Packets of prepared information were useful to some parents while others felt that those were too technical and were inaccurate.

This study was conducted with professionals and families from two centers. The results indicated that parent satisfaction with the process depended on how well the professional discussed diagnosis, prognosis, and recommendations. Thus it was implied that the professionals should spend more time on providing resources for the family and discussing the prognosis for the child.

Post diagnosis experiences

Previous research suggests that when parents first learn about their child's disability, they react with feelings of loss and mourning for the "hoped for child." (Blacher, 1984; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). This is found to be similar to the

bereavement process associated with the death of a family member or a friend (Blacher, 1984).

Initial Reactions

Blacher (1984) reviewed the literature on reactions of parents to a diagnosis of children with special needs. Based on the literature, he delineated three stages of parental adjustment to the birth of a child with handicaps. The first stage consists of an initial crisis response which includes shock, denial, and feelings of guilt, anger, depression and shame. In the next stage, parents feel emotionally disorganized at first. They recover from the shock and make themselves aware of the disability. In the third stage of adjustment, parents accept their child. They channel their energies to problem solve and think about the future of their child. At this point they may encounter other issues from concerns about financial and psychological support for their child throughout his or her life, to concerns about obtaining the best available treatment services for the child.

Nissenbaum et al., (2002) addressed parents' reactions to receiving an autism diagnosis. Professionals interviewed in this study believed that most parents' reactions to the diagnosis included denial about the diagnosis and led to many parents choosing to get a second opinion. They believed that some parents misperceived the diagnosis and thought that their child would outgrow the problems. Some parents expressed relief about receiving the diagnosis and indicated that it made it easier for them to receive support to start intervention. Other parents experienced devastation and helplessness. Parents also reacted by becoming angry or disliking the professional. Most professionals believed that the parents' reactions were dependent on the degree to which they suspected autism. Parents who were suspecting autism had positive reactions like relief, acceptance of the

diagnosis, and receptiveness to additional information; whereas, parents who were suspecting a problem other than autism had mixed positive as well as negative feelings including relief, receptiveness, denial, anger and devastation. Many parents expressed their concerns about how their spouse and extended family and friends would react to the diagnosis. The number of spouses present at the interpretive conference was not mentioned.

Harris (1984) examined the issues that the parents face surrounding the diagnosis of a child with autism. The first issue is when the parents first noticed developmental concerns with their child. Some parents may take a while to note these concerns and to be convinced that this is a serious problem which needs professional attention. This may delay seeking help and thus might affect further progress. Harris (1984) also suggested that after birth to the time when they notice concerns, parents may have created in their minds a certain set of expectations for their child. When the child's developmental concerns conflict with these expectations, they are forced to redesign their notions, which may be anxiety provoking for many parents. Thus many parents are found to "shop" for a diagnosis which does not provoke the same level of anxiety that an autism diagnosis provokes.

Family Life

Family life may be affected by the diagnosis in many ways. Couples with marital conflicts may be more distressed after receiving a diagnosis of autism than other couples (Harris, 1984). This may be due to lack of tools like sound problem solving skills and open communication (Gath, 1978).

For many parents; family life might revolve around the child with autism and thus the couple may spend less time with each other resulting in dissatisfaction with the family life. Social life may be altered to fit their child's needs and therefore may be frustrating for the parents (Moes, 1995). Working parents may be faced with the dilemma of choosing between the demands of their careers and spending quality time with their child. These parents may be forced to continue with their jobs so as to maintain the financial inflow to keep up with the increasing needs of the family.

Geographic location

Another issue that might be encountered with obtaining services after receiving a diagnosis is the geographic location of the specialized service. Parents who live in rural areas may encounter the challenges of unavailability of services in their area due to scarcity of specially trained professionals and complexity of the transportation to the urban settings and thus an increased expense for accessing these services (Gething, 1997). While Gething (1997) hypothesizes that this may be a concern, no published studies were discovered examining the issue directly. Therefore, the proposed study included an examination of rural vs. urban location and its relation to accessing services.

It is now well established that early interventions for children with developmental disabilities can be important in increasing cognitive, linguistic, social, and self-help skills (Dawson and Osterling, 1997; Rogers, 1998). The next section presents a review of studies investigating parents' and professionals' views regarding intervention services for children with autism.

Intervention and Parent Stress

Moore, McConkey, Sines and Cassidy (1999) conducted a study in Northern Ireland on parents' and professionals' opinions about early intervention which were synthesized into a set of recommendations for the field. The study was conducted in two stages, and the first stage included identification of the key attributes of the diagnostic and assessment services for children with autism. From the information collected, the research team identified the principles that should govern the services provided in Northern Ireland. The second stage consisted of validating the principles and recommendations that the research team identified. For this, four consultation/information sessions were conducted throughout Northern Ireland with parents and professionals. A written summary of these principles was sent to the respondents of the previous questionnaires to receive feedback.

Overall, it was evident from the results that specialist diagnostic services were available in some parts of Northern Ireland, while other parts lacked basic services. Parents reported frustrations about receiving diagnoses and directing them to appropriate resources. Specifically they complained of lack of information provided by the diagnosticians about the diagnosis and the consequent services. Professionals also said that they were not aware of the roles they would play in the process of obtaining services. Many professionals also were reluctant to take on the responsibility of conveying the diagnosis to parents. This was validated by professionals' comments about the diagnostic process. They thought they did not gain adequate expertise in autism during their professional training and that they had to steer themselves forward to gain further autism

specific information. The greatest difficulty that the parents faced was overall lack of provision of therapeutic intervention. However, some parents reported that the intervention care that they received was excellent. A need for a coordinator to manage all the services was suggested as in the Stallard and Lenton (1997) study.

Studies investigating the effectiveness of the various types of service delivery and types of interventions are reviewed in the subsequent sections.

Effective interventions

Early diagnosis and subsequent intervention have been vital in producing positive outcomes for children with autism. Comprehensive early intervention programs have been shown to be effective in changing the developmental course of children with autism (Bryson, Fombonne and Rogers, 2003). These programs typically include individualized teaching programs that target development in the areas of cognition, motor abilities, and self-help abilities. Various programs have proven to be effective in increasing the quality of life of children with autism. One such model is The Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) program. This model was developed in the early 1970s by Dr. Eric Schopler. It involves focusing on the person with autism and the development of a program around this person's skills, interests, and needs. Structured teaching is the primary basis of this approach (Marcus, Schopler and Lord, 2001). Parents serve as co-therapists and implement this approach successfully in home settings causing significant gains in child behavior (Ozonoff & Cathcart, 1998; Short, 1984). This model has also been shown to cause significant increases in IQ scores specifically in very young non-verbal children (Lord and Schopler, 1989). Research has shown that the rate of institutionalization was 8% in adults who had

received TEACCH intervention as compared to 39-74% rate of institutionalization in adults receiving other treatment programs. (Ozonoff & Cathcart, 1998).

Another treatment program with published outcome data is the Denver Model. The theoretical basis for Denver Model was developed based on the model of interpersonal development proposed by Daniel Stern (1985). This is a comprehensive interdisciplinary approach which draws from all expertise available in the field of autism. This program can be implemented in various treatment settings, namely a center-based model, within family routines, at the preschool and in a one-to-one interaction. This model emphasizes play, language, cognition and social relations. It has been found to significantly increase social communicative play skills, and social interaction with various partners, and thus children make significant progress in cognition, language and perceptual fine motor areas (Rogers et al, 1986).

A third program that has been shown to be effective in the treatment of children with autism is the Lovaas method or discrete trial training, which is based on the principles of applied behavior analysis. Ivar Lovaas and colleagues at University of California Los Angeles (UCLA) were among the first ones to publish the most thorough paper in 1987 on the effectiveness of a comprehensive applied behavior analytic (ABA) treatment for 40 hours weekly for 2 or more years for children with autism the during early preschool period. This study compared the progress made by three groups of children with autism. The experimental group consisted of 19 children who were provided an average of 40 hours per week of one-to-one behavioral intervention for a minimum of two years. The first control group consisted of 21 children who were given 10 hours or less per week of behavioral intervention, while the second control group consisted of 21 children not

treated by Lovaas and his colleagues. The behavioral treatment addressed all the deficits normally associated with autism spectrum disorders: cognitive, social, behavioral and communication. Results indicate that significant differences were evident between the experimental group and the two control groups. The experimental group children, as a whole, showed an average gain of 20 IQ points while the two control groups showed no gain at all. Nine children in the experimental group (47%) successfully completed regular first grade without any supports and obtained IQ scores in the average to above average range. Eight of the remaining ten children in the experimental group demonstrated substantial gains in all areas of development, but were unable to attend school without any support. They completed first grade in special education or language-delayed classes. The remaining two children were placed in classes for autistic or mentally retarded children.

In contrast, only one child in the two control groups completed regular first grade and had an IQ score in the average range. Of the children in the control groups, 53% were placed in classes for autistic or mentally retarded children, with the rest completing first grade in special education or language-delayed classes.

Furthermore, Lovaas and his colleagues published a follow-up study (McEachin, Smith, & Lovaas, 1993), in which they reevaluated the 9 best-outcome children from the original study when they were about 13 years old. In addition to measuring the IQ of these children at follow-up, two other tests, the Vineland Adaptive Behavior Scales and the Personality Inventory for Children, were used to evaluate this group. The results of the follow-up study demonstrated that the gains made by these children persisted. Eight of the 9 children continued to succeed in normal education classes. One child had been

placed in special education classes subsequent to the original study, but one child originally placed in special education classes had later been moved to regular education classes.

Overall it is clear that comprehensive and structured interventions improve outcomes for children with autism. However, it is still not clear if one program works better than the other. Previous research has been conducted on various treatment programs and their effectiveness but has failed to examine parents' preferences and experiences related to the different programs. It is important to know parents' preferences regarding the type of interventions and related experiences because it might help professionals take those into consideration while designing treatment programs.

Models of Service Delivery

Along with the type of intervention, it is important to know parents' perceptions regarding the type of service delivery that they think would reduce their burden. As the incidence of autism is increasing, the resources needed to serve these children are not sufficient to meet their needs. Professionals providing one-on-one treatment are difficult to find and expensive. Finding resources (such as specialized intervention centers for children with autism) is difficult for families living in geographically distant areas (Koegel, Symon and Koegel, 2002). Hence alternative models of service delivery are needed. In an early study, the benefits of parents as direct service providers were documented (Lovaas, Koegel, Simmons, & Long, 1973). In this study, it was evident that the groups whose parents were trained to carry out behavior therapy continued to improve, while children who were institutionalized regressed. However, it could be argued that it was not the parent training per se but just being with the parent rather than

an institution, may have caused the improvements. This approach also appears to be economical and feasible for treatment delivery (Schreibman & Koegel, 1996). In this model, parents are trained to be their child's therapists. The training consists of demonstrating and modeling various techniques to teach specific skills and manage problem behaviors (Symon, 2005).

The literature suggests that parents have successfully learned to design and implement behavioral, social, and communication programs for their children with special needs (McClanahan, Krantz, & McGee, 1982; Koegel, Bimbela, & Schreibman, 1996). However, some parents are faced with additional challenges like bringing up siblings, working outside home, and personal medical problems. Hence they are not able to take up full responsibility of teaching skills to their children with autism. For this reason, parents may need additional support and may opt for the previously discussed more expensive model of service delivery in which professionals provide services directly to the family. This may be done at a clinic or in naturalistic settings. Since each service delivery presents unique challenges in the treatment process, it may be worthwhile to examine parents' preferences of therapy models. Due to stress, some parents may choose to shift full responsibility of their child's treatment onto the therapist and thus would prefer therapist-child direct service model. This stress may also cause reverse effects on other parents, leading them to choose to take the responsibility of their child's treatment on themselves. Thus they might choose the therapist-parent consultative model.

Limitations of the Previous Literature

Despite the fact that the research on parent stress specifically with autism is relatively new, many studies have documented the high levels of stress parents experience. A few studies have evaluated the correlates of this parent stress. While 1 study (Howlin & Moore, 1997) has examined the possible correlates of stress at diagnosis, there are no studies in the literature which examined the possible correlates of stress while looking for services for their child.

There were several limitations noted in the studies mentioned above. The Smith et al. (1994) study did not examine the length of time between the first concerns of parents to the initial diagnosis. A formal scale to measure the level of parent satisfaction with the diagnostic services was not used. It was not clear whether parents received a referral for diagnostic evaluation before the diagnosis was made. It would have been important to examine whether a possible delay in obtaining a referral might have led to a delay in receiving a diagnosis. It was also not clear as to what type of assessments were conducted by the professionals to make the diagnosis of autism. This would have been important in determining whether the diagnoses made were valid and based on solid diagnostic assessments which are high in specificity and reliability for detecting autism.

Another major study Howlin and Moore, (1997) on the diagnostic issues of children with autism had several limitations. This study looked only at the delay in receiving diagnosis for children with autism and not at the delay in obtaining services after receiving the diagnosis. In spite of the regional variations in the degree of parent satisfaction, further analyses were not conducted to examine whether the location, urban

or rural, played a role in accessibility of services. This may have been an important factor in determining the level of parent satisfaction with the services received. This study also did not include parents' initial reactions and the coping styles following the diagnosis. While all of the studies described so far provided information about the age at which diagnosis is received, one of them (Smith, et al., 1994) fails to address the fact that these children may have been diagnosed more than one time. Parents may have sought a second opinion and it is not clear which diagnosis is being referred to in the questionnaire.

In one of the studies (Nissenbaum et al., 2002), the professionals chosen as participants of the study worked at the same medical center. The policies and procedures of the medical center would have been reflected in the professionals' opinions about the interpretive conference. While this study addressed parent reactions after receiving the diagnosis, it did not mention how parents coped after receiving the diagnosis.

Furthermore, there were limitations noted in the Moore et al., (1999) study. Specifically, it did not evaluate the factors that might have caused the overall lack of therapeutic intervention for parents, such as lack of awareness of services available, geographic location of the services and lack of expert personnel. They also did not take into consideration parents' opinions about ideal therapy services for their child.

Taking into consideration these limitations, the current study sought detailed information regarding parents' experiences with diagnosis and intervention. Next section deals with the purpose of the current study.

CHAPTER III

PURPOSE OF THE CURRENT STUDY

As we have discussed earlier, parents with children with autism face many challenges and these challenges may lead to high levels of parent stress. However, there has been no research to explore possible correlates of this stress experienced by parents of children with autism during the process of finding resources for their child. Understanding the factors that are linked to stress will be helpful in delineating and designing possible prevention strategies to alleviate parent stress. The current study sought to study issues related to the diagnosis and intervention services for children with autism.

Howlin and Moore (1997) found that the average age at which diagnosis was received was 6 years. Satisfaction with the diagnostic process was found to be significantly related to the geographical area where diagnosis was received, child's age at diagnosis, delay between first seeking help and confirmation of diagnosis, child's current age, and final diagnosis given. It was evident from the results that additional research on parent stress and satisfaction is necessary as parents search for an accurate diagnosis and appropriate treatment for their children.

Primary Purpose of the Study

The primary purpose of the current study was to update the results from the Howlin and Moore (1997) study. Specifically, the current study sought to update answers to the following core questions dealt with in the Howlin and Moore (1997) study: (a) Is the

diagnosis of autism being received at earlier ages than before?; and (b) Is the length of time between the referral and diagnosis compared to earlier studies? Howlin and Moore (1997) focused only on the diagnosis related issues and did not include information on when intervention services were received. Therefore, in addition to the above questions, the current study sought information on how early intervention is being received now. This study provided unique information by examining these issues from participants from the United States.

Second Purpose of the Study: Descriptive Information

Next, this study sought to describe some specific issues regarding the diagnostic and intervention process, which included: first concerns of parents; individuals who were first concerned; initial reactions of parents after they were first concerned; personnel who referred the child for a diagnostic evaluation; diagnostic tests conducted; professionals who diagnosed the child; parents' reaction, thoughts and coping strategies during the diagnostic process; parent perceptions of causes of autism; resources spent in terms of money and time on diagnosis and intervention; geographical location of diagnosis and intervention; time that professionals spent during the interpretive conference; nature and type of services received; and parent preferences about the model for intervention. Along with the information regarding parents' challenging experiences with seeking services, descriptive data regarding positive characteristics such as the child's strengths, and progress made since diagnosis were also reported.

Third Purpose: Current Stress and Satisfaction with Current Services

It was hypothesized that the current stress and satisfaction of services will be negatively correlated to each other (i.e. higher the stress, lower the satisfaction).

Therefore, this study sought to study the link between current stress and satisfaction with current services (overall and with each of the therapies).

Fourth Purpose: Possible Correlates of Stress at Diagnosis

Even though researchers have examined various aspects of parent stress during the diagnostic process, there are no studies that address the possible correlates of parent stress such as level of difficulty obtaining a diagnosis, and the child age at diagnosis.

The fourth purpose of the study was to explore the link between parent stress at diagnosis and the level of difficulty obtaining a diagnosis. It was hypothesized that higher the level of difficulty in obtaining a diagnosis, higher the level of parent stress. Next, the link between parent stress at diagnosis and the child age at diagnosis was examined using Pearson's coefficient of correlation. If the child is diagnosed earlier, then parents may experience less stress due to improvements in child's behaviors as a result of receiving intervention earlier. However, if the child is diagnosed earlier, it may be possible that the child has severe deficits to warrant an early diagnosis. Thus, it may be implied that the severity of the diagnosis may lead parents to be more stressed. Hence the direction of the hypothesis about the correlation between child age of diagnosis and parent stress at diagnosis could not be specified.

Fifth Purpose: Possible Correlates of Geographical Location

Another purpose of this study was to examine the possible correlates of geographical location such as current parent stress and parent satisfaction with current services. First of all, it was examined if the families living in urban versus rural areas differed significantly from each other based on the current stress scores. It was hypothesized that families living in rural areas would significantly differ from those living in urban areas based on

the current stress scores. Specifically, it was hypothesized that parents living in rural areas would experience more stress than those living in urban areas, due to limited accessibility to services in rural areas.

Furthermore, the parents living in rural areas were compared to those living in urban areas based on their satisfaction with intervention services. It was hypothesized that parents living in rural areas would differ significantly from those living in urban areas, based on their satisfaction with current services. More specifically, it was hypothesized that the parents living in urban areas would be more satisfied than those living in rural areas due to the greater accessibility to services in urban areas. Next, the parents living in rural areas were compared to those living in urban areas based on their satisfaction with each of the services (namely speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school, behavior therapy at home, and other services).

Sixth Purpose: Correlates of Type of Diagnosis

Next, the possible correlates of the type of diagnosis were explored such as current stress and parent satisfaction with current services. First of all, the difference in diagnostic groups based on current parent stress was explored. Secondly, the diagnostic groups were compared based on the both: the overall satisfaction with current services and level of parent satisfaction with each of the intervention services (namely speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school, behavior therapy at home, and other services).

It is possible that parents in the Autistic group would report more stress and less satisfaction than parents in the other group (which consisted of children with Asperger's disorder, and PDD-NOS) due to the relative severity of symptoms. However, it may also be possible that because it is difficult to differentiate between the subtypes of autism, children in the other group may not be diagnosed until later and as a result parents may experience difficulty obtaining a diagnosis. This may lead the other group to experience more stress and less satisfaction with services than the Autistic group. Therefore, the direction of the above two hypothesis could not be predicted.

Hypotheses

Apart from describing the information gathered from families of children with autism regarding the diagnostic and intervention process, following hypotheses were considered. First, it was hypothesized that the current stress and the overall satisfaction of services would be negatively correlated to each other (i.e. higher the stress, lower the satisfaction). Second, it was hypothesized that the current stress and the satisfaction of each of the current services (speech therapy, occupational therapy, and special education) would be negatively correlated to each other (i.e. higher the stress, lower the satisfaction). Third, it was hypothesized that higher the level of difficulty in obtaining a diagnosis, higher the levels of parent stress at diagnosis. Fourth, although the direction of the hypothesis about the correlation between child age of diagnosis and parent stress at diagnosis was not specified, it was hypothesized that these two variables would be significantly correlated. Fifth, it was hypothesized that parents living in rural areas would experience more stress than those living in urban areas, due to limited accessibility to services in rural areas. Sixth, it was hypothesized that parents living in rural areas would

differ significantly from those living in urban areas, based on the satisfaction with current services. Seventh, it was hypothesized that the diagnostic groups would differ significantly based on the current parent stress scores. Eighth, it was hypothesized that the diagnostic groups would differ significantly on satisfaction with current services.

CHAPTER IV

METHOD

Participants

Parent Characteristics

A survey of 126 parents of children with Pervasive Developmental Disorders all over the United States was conducted. Of the 126 parents, 118 (93.7%) were biological mothers, 2 (1.6%) were biological fathers, 3 (2.4%) were grandparents, and 3 (2.4%) were adoptive mothers. The parents ranged in age from 24 to 63 years ($M = 36.6$, $S.D = 6.8$). Parents from across 30 states in the United States participated in this study, representing a wide range of services received. Although participants were recruited from all over the United States representing a variety of nature of services received, there was limited heterogeneity in terms of the ethnicity of the parents. One hundred eight (89.3%) of the parents were Caucasians, 3 (2.5%) were African Americans, 6 (5.0%) were Hispanics, 3 (2.5%) were Native Americans, and 1 (.8 %) was Asian-American.

Furthermore, when asked about the marital status, 5 (4.2%) parents were never married, 73 (60.8%) were married, 26 (21.7%) were living together, 14 (11.7%) were divorced or separated, 1 (0.8%) was widowed and 1 (0.8%) reported being in a civil union.

Most (66.6%) of the parents were well educated (37 had a college degree, 6 had a partial graduate degree or professional training; and 39 had graduate or professional training). The remaining parents had partial college training (22.8%), were high school

graduates (8.9%), or had attended partial high school (1.6%). Three parents did not mention how long they went to school.

Half of the families reported their annual household income to be above or equal to \$60,000; out of which, 64% reported it to be in the range from \$61,000 to \$99,000; and 36% reported it to be above \$1, 00,000. Out of the families who had their incomes less than \$60,000 per year, 52% were in between \$40,000 and \$60,000. Twenty-three percent of all the parents reported their income to be less than \$40,000. It should be noted that one parent reported their annual household income to be one million dollars.

The number of people in the family who were working ranged from 0 to 3 ($M = 1.46$, $S.D = 0.5$). The total number of people dependent on the household income other than people working ranged from 0 to 6 ($M = 2.71$, $S.D = 1.2$). One person reported that their child was on child support and therefore was not financially dependent on the mother. Additionally, 77 % of the parents reported being affiliated to an autism organization, parent group or a parent network.

Child Characteristics

The children ranged in age from 2 to 8 years ($M = 5.13$, $S.D. = 1.69$). All had been diagnosed as being on the autism spectrum: 77 (61.1%) with Autistic disorder; 11 (8.7%) children with Asperger's disorder; 36 (28.6%) with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS); and 2 (1.6%) with Childhood Disintegrative Disorder. Three (2.3%) mentioned that their children were on the autism spectrum, but did not specify a particular category. In addition to being on the autism spectrum, 6 (4.7%) mentioned other diagnoses (2 with Attention Deficit Hyperactivity Disorder, 1 with Communication Disorder, 2 with Sensory Integration Disorder, and 1 with

Oppositional Defiant Disorder). There were no children with Rett's Disorder. It was unknown if any families had more than 1 child with autism.

Materials

Personal Information Sheet (Appendix B)

The Personal Information Sheet sought personal information about the child such as his/her name, mailing address, and telephone number. This information was used to contact parents during the study if necessary. Additionally, parents had to provide a code (consisting of first three letters of the child's last name, month and year of birth). Instead of the identifying information, this code was used for data analysis.

Early Autism Experiences Survey (Appendix C)

Parents were asked to fill out the Early Autism Experiences Survey which consisted of 80 open- and closed-ended questions. It included questions starting from the time when parents first noticed concerns to the process of obtaining intervention services. It elicited responses from the parents regarding their stress levels during this process, their coping strategies, satisfaction level with the services received and the difficulty accessing services. The Early Autism Experiences survey had a similar format and content to a survey reported by Howlin and Moore (1997) study. Due to inaccessibility of the original survey, this current survey was derived from the themes discussed in their paper including age at which parents were first concerned about their child; ages at which he was referred and then finally diagnosed; professionals seen; and general satisfaction of the diagnostic process. Additional topics that were addressed in the current survey included parents' feelings and thoughts after their child was diagnosed; their stress levels and coping mechanisms; intervention services sought after the diagnosis; degree of

difficulty in accessing diagnostic as well as intervention services; financial resources being spent each year; and the ideal therapy model that the parents would prefer.

Parental Stress Scale (PASS; Appendix D)

The fourth measure that parents completed was the Parental Stress Scale (PASS, Berry & Jones, 1995). It is a self-report scale that contains 18 items representing positive themes of parenthood (e.g. emotional benefits, self-enrichment, and personal development) as well as the negative components (e.g. demands on resources, opportunity costs and restrictions). Respondents are asked to agree or disagree with items in terms of their typical relationship with their child or children and to rate each item on a five-point scale: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5). The 8 positive items are reverse scored and summed up so that possible total scores on the scale range between 18 and 90. Higher scores on the scale indicate greater stress.

The Parental Stress Scale has demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81) (Berry & Jones, 1995). Additionally, the PASS has also demonstrated satisfactory convergent validity with various measures of stress, emotion, and role satisfaction, including perceived stress, work/family stress, loneliness, anxiety, guilt, marital satisfaction, marital commitment, job satisfaction, and social support. For example, the correlation between PASS and the Total Parenting Stress Index of the PSI was .75 (Berry & Jones, 1995). Furthermore, discriminant analyses demonstrated the ability of the scale to discriminate between parents of typically developing children and parents of children with both developmental and behavioral

problems. In the current sample, the internal reliability of the PASS was satisfactory with Cronbach's alpha coefficient of 0.85.

The PASS was used in the current study to measure levels of current stress experienced by parents while interacting with their child with autism. For the purpose of the current study, the Total Score on the PASS was used as a measure of parent stress currently being experienced. Since there are no studies supporting the use of PASS in documenting retrospective stress, the stress experienced during diagnostic process was measured using a 7-point Likert scale (1 = Not at all difficult; 7 = Extremely Difficult).

Perceived Stress Scale (Appendix E)

In addition to the Parental Stress Scale, the Perceived Stress Scale (PSS, Cohen, S., Kamarck, T., & Mermelstein, R., 1983) was used to measure general stress experienced in everyday life, not specific to the role of a parent. The PSS is available as 4-, 10- and 14-item self-report instrument. For this study, the PSS-10 item questionnaire was used. The possible scores on the scale can range from 0-40, with higher scores indicating higher stress. It demonstrates strong internal consistency with a Cronbach's alpha of .85. In the current sample, the internal reliability of the PSS was satisfactory with Cronbach's alpha coefficient of 0.88.

Respondents were asked to describe the frequency of their feelings and thoughts in the last month on a 5-point scale (0 = never; 1= almost never; 2 = sometimes; 3 = fairly often; 4 = often). PSS-10 scores were obtained by reversing the scores on the four positive items, (e.g., 0=4, 1=3, 2=2, etc.) and then summing across all 10 items to obtain a Total PSS score. For the purpose of this study, the total PSS score was used as a measure of current stress experienced by parents, alongwith the total PASS score.

Demographic Questionnaire (Appendix F)

Finally, a demographic questionnaire was filled by parents which consisted of information regarding the age of the parent, gender, marital status, number of family members, annual household income, area of residence, level of education, & affiliation to any parent support groups or organizations.

Procedure

Parents were required to complete the above-mentioned 5 forms which were either sent through regular mail or were available online. First, parents completed the informed consent form (Appendix A). The informed consent provided information about the purpose, risks, and benefits of the survey. Parents were provided the opportunity to refuse to participate in the survey if they so wished.

Initially this study was conducted in two formats; online and paper-based. The Microsoft FrontPage software was used to design the online version of the study. The information collected from the Personal information sheet was stored in a separate secure database on the Oklahoma State University server. After completing this information, they were directed to another page which consisted of all the measures used in the study. The information provided was stored in another file on the Oklahoma State University server. However, due to technological difficulties, the online version was discontinued after 11 participants, after which only the paper-based format was used.

For the paper-based survey, once the survey was returned, the personal identifying information was entered in a separate database and was stored along with the informed consent in a locked cabinet.

Participants were initially recruited only from Oklahoma through local parent autism networks. The survey was distributed via regular mail or direct contact. Participants from previous studies who had consented to being contacted for further studies were sent study packets. The study was further publicized by providing information about the study at the local parent network meetings. Another method used for soliciting participants was placing descriptions of the study in autism online group emails. To ensure active participation, reminders were sent to the parent network leaders via email, one month after distributing the announcement for the first time.

Thirty parents were recruited through regional parent autism networks in Oklahoma. A priori power analyses had revealed that a minimum of 118 participants would be needed to yield 80% power to detect a medium effect size. To meet that goal, additional participants from all over the United States were solicited. Researchers at Kennedy Krieger Institute, Johns Hopkins University, Baltimore, Maryland agreed to assist in recruiting participants for the study through the Interactive Autism Network (IAN). IAN is designed to accelerate the pace of autism research by linking researchers and families. Interested participants requested that the researchers send packets to them. It should be noted that post-hoc power analysis was also conducted (See Results).

Once the parents received the packets, they were given two weeks to complete and return the packets. Reminder emails were sent two weeks after sending the packets to parents who did not return the packets. Ninety-six parents (out of 150) solicited through the IAN, returned the survey packets.

Finally, those who participated were sent emails thanking them for their participation. They were provided a list of topics for resource information to choose

from. These topics included Special Education and Law, Asperger's Disorder, Toilet Training, Social Skills, Language and Communication and Adolescent Issues. After they completed the study, parents were sent relevant articles on each of the topics that they requested. This information was either sent via mail (for initial group from Oklahoma) or electronic mail (for those who were recruited through IAN).

CHAPTER V

RESULTS

Age of First Concerns, Referral, Diagnosis and Intervention

The primary purpose of our study was to elaborate on and update previous work by Howlin and Moore (1997). Specifically, the current study sought to update answers to the following core questions dealt with in the Howlin and Moore (1997) study: (a) Is the diagnosis of autism being received at earlier ages than before?; and (b) Is the length of time between the referral and diagnosis reduced compared to earlier studies?

The average age at which children in the current sample were diagnosed for the first time was 3.09 years (*S.D.* = 1.32, range = 1-7.4 years). The results of the Howlin and Moore (1997) study showed that the average age of diagnosis was 6 years in the United Kingdom sample, thus affirming that the diagnosis is being received earlier now. One sample z-test confirmed that the two means differed significantly from each other ($z = -7.48, p < 0.001$).

The duration of time from first referral to diagnosis was calculated by subtracting the age of referral from the age at which the first diagnosis was received. The average duration of time was .68 years (*S.D.* = .96, range = -4.00 to 4.75). The negative range suggested that children had received services even before they were formally referred. As compared to the results of the previous study (Howlin and Moore, 1997), in which the duration from first referral to diagnosis was reported to be 3.81 years in the United

Kingdom sample, the children in the current study experienced a shorter delay in diagnosis.

In addition to the above questions, the current study sought information on how early intervention is being received now. Howlin and Moore (1997) focused only on the diagnosis related issues and did not include information on when intervention services were received. The results of the current study showed that the mean age at which children received services after the diagnosis was found to be 2.83 years (*S.D.* = 1.34, range = 0-7.3).

Furthermore, the current study sought information on the age of first concerns and age of referral. The average age at which parents noticed first concerns was 1.48 years (*S.D.* = 0.86, range = 0 – 4.6 years). The average age when children were referred for evaluation was 2.45 years (*S.D.* = 1.19, range = 0 -7 years), indicating that some children were referred at birth.

The categories for the age of first concern, referral, and diagnosis are summarized in Table 1.

Another purpose of this study was to provide descriptive data on following variables: first concerns of parents; individuals who were first concerned; initial reactions of parents after they were first concerned; personnel who referred the child for a diagnostic evaluation; diagnostic tests conducted; professionals who diagnosed the child; parents' reaction, thoughts and coping strategies during the diagnostic process; parent perceptions of causes of autism; resources spent in terms of money and time on diagnosis and intervention; geographical location of diagnosis and intervention; time that professionals spent in discussing the diagnosis, parents' reactions to the diagnosis, and

recommendations; nature and type of services received; and parent preferences about the model for intervention. Along with the information regarding parents' challenging experiences with seeking services, descriptive data regarding positive characteristics such as the child's strengths, and progress made since diagnosis were also reported.

Descriptive statistics (Mean, Standard Deviation, and Range) for all the variables were obtained. The descriptive data obtained are described below.

First Concerns

Parents were asked to provide information regarding their first concerns about their child. One hundred fourteen (90.5%) respondents reported that they themselves first noticed concerns. Others who first noticed concerns were: family (33.3%); spouse (30.2%); pediatrician (8.7%); friend (6.3%); teacher (4.8%); primary care physician (4.8%); day care personnel (6.3%); and other people (7.1%) including speech therapist, orthopedic specialist, physical therapist, ENT physician, psychologist, and a public health nurse.

The first concerns that the parents noticed were speech delays (60.3%), transition difficulties (44.4%), solitary play (41.3%), lack of eye contact (36.5%), developmental delays (32.5%), echolalia (15.1%), insufficient amount of speech (40.5%) and talking in language much higher for child's age (5.6%). Others reported stereotypical behaviors (5.6%), feeding issues (5.6%), sleep issues (5.6%), failure to respond to name (4.8%), problems in group situations (4%), general behavior problems (5.6%), lack of eye contact as a new born (4%), and sensory issues (4%). Very few parents noted self-injurious behaviors (2.4%), lack of pretend play (1.6%), eating non-edible food (1.6%), and lack of pointing (1.6%) as their first concerns.

Initial Reactions

Parents were asked to discuss their initial reactions when they first noticed concerns. All parents endorsed more than one initial reaction. Out of the 126 parents who responded to this item, 61.1% reported expressing concerns to their family and 39.7% to their friends. While some (42.1%), thought that their child would outgrow the problem, 15.9% were in denial. Additionally, 34.9% contacted the pediatrician immediately, 31% searched the web for more information and 4% joined online support groups. While 16.6% of the parents sought professional help for their child immediately after being concerned, 3.2% reported being so worried that they had to seek professional help for themselves. Very few parents (4%) reported emotional reactions such as feeling sad, upset, angry, overwhelmed, helpless, and blaming self.

Referral, First Diagnosis and Second Opinion Diagnosis

One hundred twenty-six parents reported that the professionals who referred the child for a diagnostic evaluation consisted of primary care physician (15.9%), pediatrician (46%), teacher (6.3%), school psychologist (2.4%), and a specialty clinic (4.8%). Others (19%) reported being referred by an audiologist, family, ENT specialist, speech therapist, family therapist, and psychiatrist. Fifteen percent of the parents reported that they referred their child for an evaluation. It should be noted that parents endorsed more than one professional who referred their child for a diagnostic evaluation.

Parents sought diagnostic evaluations for their children and these diagnostic evaluations conducted by the professionals are summarized in Table 2.

As mentioned in the above table, 29.4% percent of the parents reported other diagnostic tests such as a variety of behavior rating scales (such as Child Behavior

Checklist, Child Symptom Inventory and Behavior Assessment System for Children); adaptive behavior scales (such as Scales of Independent behavior, and Vineland Adaptive behavior Scale); developmental tests (such as Beery-Buktenica Test of Visual-Motor Integration, Bayley's Developmental Test, Peabody Developmental Test, Gesell Developmental Schedules Test, Battelle Developmental Inventory, and Hawaii Early Learning Profile); language tests (such as Expressive Vocabulary Test, Rossetti Infant Toddler Language Scale, and Preschool Language Scale); and standardized cognitive tests (such as Differential Ability Scales, Bracken Basic Concept Scale, and Wechsler Preschool and Primary Scale of Intelligence). Only 1 parent reported that only direct observation was used to diagnose their child.

One hundred twenty-six parents reported that their child was diagnosed for the first time by a number of professionals; including: clinical child psychologist (35.7%); pediatrician (18.3%); specialty clinic or a team of professionals (15.9%); psychiatrist (8.7%); school psychologist (4.8%); state department case worker (2.4%); primary care physician (1.6%); and other professionals (12.7%) namely neurologist, infant developmental specialist, neuropsychologist, and speech therapist.

The initial diagnoses received by the children were Autistic disorder (44.8%), Asperger's Disorder (7.1%), Pervasive Developmental Disorder Not Otherwise Specified (42.4%), and Childhood Disintegrative Disorder (0.8%). Nineteen parents reported other diagnoses such as Attention Deficit Hyperactivity Disorder, Landau-Kleffner Syndrome, Developmental Delay, Mixed Receptive –Expressive Language Disorder, Oppositional Defiant Disorder, Regulatory Dysfunction Disorder, Sensory Integration Disorder, and Symbolic Dysfunction. Four parents reported that their children were diagnosed as being

on the autism spectrum, but no specific categories were provided. Only 1 parent reported that after a diagnostic evaluation, the doctor said that their child was fine and that the parent was overreacting. It should be noted that parents reported more than one diagnosis on this question.

Forty-four (35.2%) parents mentioned that they sought a second opinion for the diagnosis. Out of these 44, 8 parents did not report the diagnosis received for the second time. Therefore, out of the 36 parents who reported the second diagnosis, 17 (48.6%) parents mentioned that the diagnosis remained the same the second time. These parents reported a variety of measures that were used to diagnose their child the second time including Autism Diagnostic Observation Schedule (24.4%), Mullen's Scales for Early Developmental (2.3%), Autism Diagnostic Interview-Revised (4.4%), Gilliam Autism Rating Scale (11.6%), Childhood Autism Rating Scale (24.4%), Asperger Syndrome Diagnostic Scale (4.4%), Adaptive Behavior Scale (15.6%), and other (28.9%). Other tests that were reported were behavior rating scales (such as Behavior Assessment System for Children), adaptive behavior scales (such as Scales of Independent behavior and Vineland Adaptive Behavior Scale), developmental tests (such as Developmental Profile-II, and Developmental Test of Visual Motor Integration), standardized cognitive tests (such as Wechsler Preschool and Primary Scale of Intelligence, Wechsler Intelligence Scale for Children, Bracken Concept Scale, and Woodcock Johnson- II) and neurological tests (MRI and EEG). Twenty (40.8%) parents did not report any information about the diagnostic tests conducted.

Fifty parents reported the mean age when the second diagnosis was received or the previous diagnosis was confirmed, to be 3.61 (*S.D.* = 1.6, range = 1.6 - 8.0). While 44

parents reported that they sought a second opinion diagnosis, 50 people reported the age when the second opinion diagnosis was received or previous diagnosis was confirmed. This discrepancy was found to be due to inconsistent responding in this section. It may have been possible that parents did not comprehend the question well. Therefore the results on the second opinion diagnosis may be interpreted with caution.

Most Recent Diagnosis

The age at which most recent diagnosis was received ranged from 1 to 8 years ($M = 3.68$, $S.D. = 1.46$). Sixty-eight percent of the children received the recent diagnosis when they were younger than 4 years. This recent diagnosis was made by family doctor (1.6%), pediatrician (15.4%), psychiatrist (7.3%), clinical child psychologist (32.5%), school psychologist (8.9%), state case worker (1.6%), specialty clinic (15.4%), or other (17.1%) professionals. Other professionals who diagnosed the child recently were neurologist, pediatric neurologist, and neuropsychologist.

Parents were asked to list strengths of their child noted during the diagnostic assessment. Twenty-four parents did not report any strengths for their child. The remaining parents (102) noted various strengths and the themes that emerged in their responses were being affectionate, caring, and easy tempered, making eye contact, being intelligent, not being as rigid, being co-operative, having an expressive face, being playful, being determined, being focused, having superior verbal proficiency, having excellent visual memory, being a quick learner, being enthusiastic, having good reading ability, using toys functionally, and being friendly.

Post Diagnosis Reactions, Thoughts and Coping Strategies

Parents were asked to describe how they reacted to their child's diagnosis. These descriptions are summarized in Table 3.

In addition to above post diagnosis reactions (Table 3.), very few (2.4%) parents reported that they thought the doctor did not know the child well enough to make a diagnosis, and even fewer (1.6%) noted that they thought the doctor did not know what he was talking about. Only 1 (0.8%) parent mentioned that he/she sought another opinion as a reaction to his/her child's first diagnosis. Forty percent of the parents also reported other reactions such as feeling overwhelmed, depressed, scared, frustrated, and upset, being prepared to hear the diagnosis, and beginning to research autism in the hope of finding the best therapy. It was interesting to note that one parent reported that her "dreams had shifted, but also felt hopeful and happy to have a diagnosis."

When asked about what their thoughts were after the diagnosis, 33 parents reported other thoughts apart from those mentioned in Table 3. These other thoughts included concerns about own mental health, concerns about caring for their child, concerns about family, concerns about child's future, concerns about other children being affected, and concerns about the child's schooling.

Furthermore, parents' perceptions about the causes of autism for their child were explored. It should be noted that parents could check more than one option on this question. Sixty-two percent supposed hereditary factors; 43.7% thought that the vaccinations may have caused autism; 33.3% thought that the child's brain structure may be responsible; 23.0% reported birth complications; 4% reported their own behavior and

19.8% thought that the chemical imbalance within the child may have caused autism. Additionally, 48.4% of the parents reported other possible causes such as environmental factors, brain-gut connection, chemicals in food, immune response, antibiotics, household chemicals, and a combination of factors.

In order to understand how parents coped after getting a diagnosis, they were asked to provide information on the strategies that were used to cope with the emotional turmoil when their child was diagnosed. The coping strategies are summarized in Table 4.

Thirty parents reported other strategies which consisted of contacting the professionals to get services, exercising, collecting more information about the disorder, starting an autism group for families, and focusing on family issues. One parent reported taking medications for his/her depression as a coping strategy.

Post Diagnosis Help

Parents were asked how they knew what to do next after getting a diagnosis. Parents endorsed more than one option on this question. One hundred twenty-five parents reported that they followed their doctor's advice (40%), contacted agencies to which the clinician had made referrals to (44.8%), searched for information and contacted agencies on their own (59.2%), depended on friends for information (31.2%), collected information from the internet (80.8%), read books and tried following recommendations from reading (65.6%), joined a local network of families with similar diagnosis (32.0%), and other methods (23.2%). These other methods consisted of talking to professionals, attending autism conferences, and networking with families of children with autism. It was interesting that 7.2% of the parents reported that they had already been receiving services even before the diagnosis and continued with them thereafter.

Most of the parents (56%) stated that they sought help within a week of getting a diagnosis. Furthermore, 19.2% reported that they sought services more than a week, but less than a month from the diagnosis. A few (5.6%) parents reported getting services 1-3 months after the diagnosis. Even fewer (3.2%) parents stated that they received services more than 3 months after the diagnosis. Twenty parents mentioned that their child was already receiving services before the diagnosis was given. It should be noted that none of the parents mentioned that they did not seek services for their child because they thought he/she would outgrow the problem.

After seeking information, one hundred twenty-five parents recounted the next step after the diagnosis. Sixty-four percent started services immediately, 50.4% talked to school about getting services, 30.4% sought professional help, and 17.6% visited a specialist. Other approaches (27.2%) described were consultation with professionals; thinking of financial support and medications; moving for services; home schooling their child; educating themselves; and taking legal action to get services. Out of these 27.2%, 13 parents reported that they continued with the services that were in place for them. It should be noted that parents could check more than one option on this question.

Time Spent by Professional During the Feedback Session of Diagnosis

Parent stress may be correlated with the amount of time the professional spent in the interpretive conference while breaking the diagnosis. Thus parents were asked to state how much time the professional spent on initial discussions about the disorder, discussions about their reactions and the possibilities of seeking interventions. These are summarized in Table 5.

One hundred twenty-one (96.8%) parents reported that the professional spent time with them discussing the diagnosis of their child. Out of these 121 parents, 71% reported that the professional spent half a session, more than half a session or one full session with them. While 92 (73%) parents reported that the professional spent time with them discussing their reactions, only 45% of these reported that the professional spent half a session, more than half a session or one full session discussing these reactions. While 97 (78.2%) parents stated that the professional spent time discussing the possibilities of seeking interventions, only 53% of these parents stated that the professional spent half a session, more than half a session or one full session. To further explore parents' perceptions about the time spent by the professional during the interpretive conference, parents were asked to rate the following statement, "It would have been helpful if the professional making the diagnosis would have spent time in discussing the prognosis and the future recommendations for my child." On a 7-point Likert scale (1 = strongly disagree; 7 = strongly agree), 66.6% parents agreed (i.e. fell on a continuum from agreed to strongly agreed), 12.7% were neutral and the remaining (20.6%) disagreed (i.e. fell on a continuum from disagree to strongly disagree).

Intervention Services

As mentioned before, the mean age at which children received services after the diagnosis was 2.83 years (*S.D.* = 1.34, range = 0-7.3). All parents (*N* = 126) reported the nature of first services received after the diagnosis. Since it was supposed that children receive a variety of services, parents were expected to check more than one option on this question. Out of these, 55.6% children received school-based services, 43.7% home-based services, 32.5% state-funded services, 27.8% clinic-based services, and 20.6 %

received other services. In the “other services,” parents reported the type of programs that were followed (e.g. cranial therapy, speech therapy, ABA, etc.) instead of the nature of services received. When asked about the type of programs that were followed, 31.2% reported following Applied Behavior Analysis (ABA), 4% followed the TEACHH model, and 2.4% followed the Denver Model. Additionally, 8.8% of the parents reported that they did not know the type of therapy that was followed, 15.2% reported that nothing specific was being followed, and 59.2% reported other programs. These other programs included adaptive music, auditory training, cranio-sacral therapy, Reiki, nutritional/diet therapy, Relationship Development Intervention, cognitive behavior therapy, naturopathy, Floor time, social skills training, melatonin, Communicating Partners, incidental teaching, sensory integration and Picture Exchange Communication System.

Next, parents were asked to describe the type of services and number of hours spent in each of the areas (namely speech therapy, occupational therapy and special education) received for the first time after diagnosis. These descriptions are summarized in Table 6.

It should be noted that the outliers (16, 25, 26, and 43 hours) were excluded while calculating the mean for speech therapy because they were more than 3 standard deviations away from the mean ($M = 1.85$). Similarly, the outliers (15, 25, and 60 hours) were excluded while calculating the mean for occupational therapy because they were also more than 3 standard deviations from the mean ($M = 1.45$). The mean number of hours for special education did not seem to represent the data well and therefore the percentages in each of the categories were reported. Forty-six percent of the children received less than 10 hours, 32.5% received 10-20 hours, and 21.3% received more than 20 hours of special education services.

Some children may have discontinued services, continued with the same services, or changed services after the first intervention. Therefore, it was necessary to explore the nature of current services being received by children. Since it was supposed that children receive a variety of services, parents were expected to check more than one option on this question. One hundred twenty parents reported the nature of current services being received. Out of these, 74.2% children received school-based services, 34.2% home-based services, 28.3% clinic-based services, 12.5% state-funded services, and 9.2% received other services. In the “other services,” parents reported the type of programs that were followed (e.g. family therapy, physiotherapy, speech therapy, and occupational therapy) instead of the nature of services being received. When asked about the type of programs that were followed, 24.4% reported following Applied Behavior Analysis (ABA), 10.1% following the TEACHH model, and 1.7% following the Denver Model. Fourteen percent of the parents reported that they did not know the type of therapy that was followed, 19.3% reported that nothing specific was followed, and 43.7% reported other programs. These other programs included adaptive physical education, point system, hippotherapy, dietary interventions, neurofeedback, biomedical regimes, cognitive behavior therapy, floor time, social skills training, Communicating Partners, incidental teaching, and sensory integration.

Furthermore, parents described the nature of services being currently received in each of the areas (namely speech therapy, occupational therapy and special education). Parents could endorse more than one option on this question. A summary of the nature of services alongwith the numbers of hours spent in each therapy per week are presented in Table 7.

It should be noted that while calculating the mean for current speech therapy hours, the outliers (13.5, 20.5, 32, and 40 hours) were excluded because they were more than 3 standard deviations away from the mean ($M = 1.80$). Similarly for the mean of occupational therapy hours, the outlier (60 hours) was excluded since it was also more than 3 standard deviations away from the mean ($M = 1.47$).

Time and Money Spent in Diagnosis and Intervention

Resources that parents spent during diagnosis and interventions, in terms of money and time, were explored. The average amount of money spent by parents on diagnosis was \$759. Although, the majority of the parents (81.6%) reported to have spent less than \$1000 on the diagnosis, 64.5% of them spent none or less than \$100 on the diagnosis. It was noteworthy that one parent reported spending \$100,000 on the diagnosis of his/her child.

When asked how much money was spent on the first intervention services, 80 parents (78.4%) reported that they spent less than \$10,000 with 60% of them spending none or less than \$100. When asked to state how much money they are currently spending each year on intervention services, 94 (65.9%) parents reported spending less than \$20,000 with 48 (51%) of them spending no money on intervention services.

In order to understand the nature of stress that parents face, it was necessary to explore how much time parents spent every week on intervention services (immediate post diagnosis as well as current) for their child. Out of 103 parents who reported the number of hours they spent on intervention each week, 10.6% parents reported that they spent no time every week on the immediate post diagnosis intervention. Furthermore, 27.1% reported that they spent less than 5 hours, 18.4% spent 5-10 hours, 27.1% spent

10-20 hours, 13.5% spent 20-40 hours, and 2.9% spent more than 40 hours a week on intervention. Out of 114 parents who reported the number of hours that they spent on current intervention each week, 9.6% spent no time on intervention every week, 26.3% spent less than 5 hours, 21.9% spent 5-10 hours, 21.9 % spent 10-20 hours, 14% spent 20-40 hours, and 6.1% spent more than 40 hours per week on intervention.

Geographical Location

In order to examine the accessibility of services, parents were asked how many miles they have to travel to get intervention services every week. These are summarized in the Table 8.

Parents were asked the geographical location (city, state and population) where the most recent diagnosis was received. The population that parents reported about the city that they received the diagnosis in, was verified using the 2006 population estimates from the U.S. Census Bureau website (<http://www.census.gov/popest/cities/>). According to the U.S. Census Bureau, geographical location can be divided into three areas namely, urbanized areas (UA), urbanized clusters, and rural areas. Urbanized area consists of contiguous, densely settled census block groups and census blocks (at least 500 people per square mile) that together encompass a population of more than 50,000. Urban cluster consists of contiguous, densely settled block groups and census blocks (500 people per square mile) that together encompass a population of at least 2,500 people but less than 50,000 people. Rural area is defined as all population and territory that is not an urbanized area or urbanized cluster. Therefore, the locations that parents provided were converted to urbanized areas or urban cluster/rural areas based on the above criteria. Thirty-four parents reported being from rural and urban cluster areas (population less

than 50,000). The percentages of parents from each of the geographical locations are described in Table 9.

Parent Stress

Information about parent stress was tapped using a variety of questions along with the stress measures. Parents were asked to report the level of stress they experienced when their child was diagnosed, on a 7-point Likert scale. One hundred seven (84.9%) parents placed their stress levels on the continuum from moderately stressed to extremely stressed. The percentages of parent reports of stress are summarized in Table 10.

Current levels of stress were explored with the help of the stress measures such as the Parent Stress Scale and the Perceived Stress Scale. The percentages of Total scores of each of the measures are provided in Table 11.

Satisfaction of services

Parents' satisfaction with the services may provide us with valuable information about how professionals can make changes to the existent services. Therefore, parents were asked to rate certain statements related to their satisfaction about the diagnostic services. It was examined whether parents wished their child were diagnosed earlier. One hundred twenty-five parents rated this statement on a 7-point Likert scale (1 = Strongly disagree, and 7 = Strongly agree). Out of these 125, 66.4% of the parents agreed, 18.4% parents were neutral, and 15.2% parents disagreed that their child should have been diagnosed earlier. Furthermore, it was necessary to know the level of difficulty that parents experienced in finding resources to get a diagnostic assessment. Out of 126 parents who completed this item, while, 34.1% found it little or not at all difficult to find resources, 66% reported finding it somewhat difficult to extremely difficult.

Parents' perceptions of satisfaction with their current intervention were sought. Overall satisfaction with the current services was reflected in the item which asked parents to rate their satisfaction on a 7-point Likert scale (1 = Not at all satisfied, and 7 = fully satisfied). Out of 125 parents who completed this item, only 3.2% were not at all satisfied with the current services. The remaining reported being minimally satisfied (6.4%), mildly satisfied (13.6%), neutral (16.8%), moderately satisfied (15.2%), highly satisfied (27.2%), and fully satisfied (17.6%). Additionally, parents were asked to rate their satisfaction in each of the therapies that they were receiving. These data are summarized in Table 12.

In order to tap further into parent satisfaction with intervention services, parents were asked to rate the statement, "I wish my child would have started receiving intervention at an earlier age," on a 7-point (1 = Strongly disagree, and 7 = Strongly agree) Likert rating scale. Of the 126 participants who responded, 6.3% strongly disagreed, 7.9% moderately disagreed, 0.8% simply disagreed, 21.4% were neutral, 12.7% simply agreed, 7.1% moderately agreed and 43.7% strongly agreed.

Finally, parents were asked if they were satisfied with the way therapy was working for their child. Out of 125 parents who responded to this question, 64% agreed. The remaining parents either were neutral (18.4%), disagreed (8.8%), moderately disagreed (5.6%), or strongly disagreed (3.2%).

Therapy Model Preferences

Parent's preferences about the model of therapy were assessed. Parents were asked to choose from the therapy model that they prefer the most. It should be noted that parents could check more than one option on this question. Out of 125 parents who responded,

28% preferred the therapist-child direct intervention model, 12% preferred the therapist-parent consultative model, 67.2% preferred both (therapist-child, parent consultative models), 3.2% preferred the therapist train-the-trainer model and 4% preferred other models. Parents' suggestions of other models included therapist and peers model, and parents being able to train themselves. One parent suggested that he/she would prefer a "social therapist," who would be responsible for helping their child apply the behavior learned in the classroom to generalize in the real world. Parents' preferences about these therapy models were further evaluated by asking them to respond on a 7-point Likert scale (1 = Strongly disagree, and 7 = Strongly agree). These data are presented in Table 13.

Current status of the child

Parents were asked to mark the level of progress that their child has made since they were first concerned. Parent report of progress of their child was measured on a 7-point Likert scale (1 = No progress; 7 = Excellent progress). Out of 124 parents who reported the status of progress, 73.4% reported that their child has made good to excellent progress. The remaining parents reported that their child has made moderate progress (17.7%), some progress (4.0%), or minimal progress (4.8%). Parents also listed current strengths of their child including being attentive, having comprehensible speech, being caring, being academically skilled, having strong visual motor skills, being self-aware, having a desire to be social, being adaptive to new situations, being an enthusiastic learner, being responsive to natural reinforcements, and having improved handwriting, and social skills. Parents were finally asked to list current needs of their child. These included deficits in adaptive skills, imitative play, self-regulation, emotional expression,

pragmatics of language, problem solving skills, fine-motor skills, oral-motor skills, reciprocal communication, and social skills. Parents also commented that they would like to see further improvement in language, further parent training to be able to handle their child at home, and sibling support.

Current Stress and Satisfaction with Current Services

The link between current stress and satisfaction with current services was explored using the Pearson's correlation coefficient. It was hypothesized that the current stress and satisfaction of services will be negatively correlated to each other (i.e. higher the stress, lower the satisfaction). The total score on the Parental Stress Scale and the total score on the Perceived Stress Scale were considered measures of current stress and were entered separately to obtain Pearson's coefficients of correlation.

It was found that the current stress as reflected by the scores on the Parental Stress Scale, was not significantly correlated with parental ratings of overall satisfaction of current services (Pearson $r = -.10$, $p = 0.24$). The current stress as measured by the Perceived Stress Scale, was also not significantly correlated with parents' ratings of overall satisfaction of current services (Pearson $r = - 0.10$, $p = 0.24$).

Furthermore, the link between current stress and parents' satisfaction with each of the services (namely speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school, behavior therapy at home, and other services) was explored separately using Pearson's coefficient of correlation. Both the scores (PASS as well as the PSS) were entered separately to obtain correlation coefficients for each of the therapies.

The correlations between Perceived Stress Scale scores, Parental Stress Scale scores and parent satisfaction with each of the therapies (speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school and behavior therapy at home) were not significant. The correlations between the Perceived Stress Scale, Parental Stress Scale and parent satisfaction with each of the therapies are reported in Table 14.

Possible Correlates of Parent Stress at Diagnosis

The link between the stress that parents experienced after obtaining a diagnosis and the level of difficulty obtaining a diagnosis was also explored. It was hypothesized that the stress experienced at the time of diagnosis may be positively correlated with the level of difficulty obtaining the diagnosis (i.e. more difficulty experienced obtaining the diagnosis, higher the stress). Stress at diagnosis was rated on a 7-point Likert scale (1 = Not at all stressed; 7 = Extremely Stressed) and level of difficulty was also rated on a 7-point Likert scale (1 = Not at all difficult; 7 = Extremely difficult). Both the variables were entered to obtain a Pearson's coefficient of correlation. It was found that the correlation between stress at diagnosis and the level of difficulty obtaining a diagnosis was not significant (Pearson $r = 0.01$, $p = 0.89$). The value of Pearson's coefficient of correlation suggests that there was almost near-zero correlation between the two variables.

Next, the link between the child age of diagnosis and stress at diagnosis was examined using Pearson's coefficient of correlation. If the child is diagnosed earlier, then parents may experience less stress as a result of improvements in child's behaviors due to early intervention. However, if the child is diagnosed earlier, it may be possible that the

child has severe deficits to warrant an early diagnosis. Thus, it may be implied that the severity of the diagnosis may lead parents to be more stressed. Hence the direction of the hypothesis about the correlation between child age of diagnosis and parent stress at diagnosis was not specified. It was found that correlation between child's age at diagnosis and parent stress at diagnosis was not significant (Pearson $r = -0.14$, $p = 0.11$).

Geographical Location and Current Stress

To examine if the parents living in urban versus rural areas differed significantly from each other based on the current stress scores, separate univariate Analyses of Variance (ANOVA) were conducted for each of the measures of stress. It was hypothesized that parents living in rural areas significantly would differ from those living in urban areas based on the current stress scores. Specifically, it was hypothesized that parents living in rural areas would experience more stress than those living in urban areas, due to limited accessibility to services in rural areas.

It was found that the parents living in rural areas (Population of less than 50,000; $M = 41.5$, $S.D. = 8.9$) did not differ significantly [$F(1, 114) = 1.71$, $p = 0.18$, partial eta-squared = 0.01, power = 0.26] from those living in urban areas (50,000 and above; $M = 43.9$, $S.D. = 10.8$) based on Parental Stress scores. The parents living in rural areas (Population of less than 50,000; $M = 19.4$, $S.D. = 6.4$) did not differ significantly [$F(1, 113) = 0.15$, $p = 0.69$, partial eta-squared = 0.00, power = 0.05] from those living in urban areas (50,000 and above; $M = 19.9$, $S.D. = 7.0$) based on the Perceived Stress Scale scores.

Geographical Location and Satisfaction with Current Intervention Services

The parents living in rural areas were compared to those living in urban areas based on satisfaction with intervention services. It was hypothesized that parents living in rural areas would differ significantly from those living in urban areas. More specifically, the parents living in urban areas would be more satisfied than those living in rural areas due to the differences in accessibility to services. Parents reported their overall satisfaction as well as satisfaction with each of the therapies on a 7-point Likert scale (1 = Not at all satisfied; 7 = Fully satisfied).

The parents living in rural areas ($M = 4.7$, $S.D. = 1.78$) and those living in urban areas ($M = 5.0$, $S.D. = 1.59$) were not significantly different from each other based on the parental ratings of overall satisfaction levels with current services [$F(1, 114) = 0.76$, $p = 0.38$, partial eta-squared = 0.00, power = 0.14].

Next, the parents living in rural areas were compared to those living in urban areas based on their satisfaction with each of the services (namely speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school, behavior therapy at home, and other services) was explored using separate univariate ANOVA. The parents living in rural areas were not significantly different than those living in urban areas based on their satisfaction of each of the following services: speech therapy at school [$F(1, 99) = 1.47$, $p = 0.22$, partial eta-squared = 0.01, power = 0.22]; private speech therapy [$F(1, 54) = 0.52$, $p = 0.47$, partial eta-squared = 0.01, power = 0.11]; occupational therapy at school [$F(1, 98) = 0.38$, $p = 0.53$, partial eta-squared = 0.00, power = 0.09]; private occupational therapy [$F(1, 47) = 0.32$, $p = 0.57$, partial eta-squared = 0.00, power = 0.08]; special education at school [F

(1, 98) = 0.16, $p = 0.68$, partial eta-squared = 0.00, power = 0.06]; behavior therapy at home [$F(1, 59) = 0.59$, $p = 0.44$, partial eta-squared = 0.01, power = 0.11]; and other services [$F(1, 52) = 1.77$, $p = 0.18$, partial eta-squared = 0.03, power = 0.25].

Type of Diagnosis and Parent Stress

Next, the difference in diagnostic groups (Autistic disorder, Asperger's disorder, and PDD-NOS) based on current parent stress was explored using one-way ANOVA. It may be possible that parents in the Autistic group would report more stress and less satisfaction than parents in the other group due to the relative severity of symptoms. However, it may also be possible that because it is difficult to differentiate between the subtypes of autism, children in the other group may not be diagnosed until later and as a result parents may report experiencing difficulty obtaining a diagnosis. This may lead the other group to experience more stress and less satisfaction with services than the Autistic group. Therefore, the direction of this hypothesis was not predicted.

The number of participants in the Asperger's, Childhood Disintegrative Disorder, and PDD-NOS were not sufficient to group individually. Therefore, the 2 diagnostic categories were considered for ANOVA. The Autism group consisted of 77 children with Autism; and the other group consisted of 45 children with other Pervasive Developmental Disorders (PDD-NOS, and Asperger's disorder). First of all, it was found that the difference between the two groups (autistic group versus other group) based on current stress as reflected by the Parental Stress Scale Scores was not significant [$F(1, 120) = 0.29$, $p = 0.58$, partial eta-squared = 0.00, power = 0.08].

Next the difference between the groups based on the Perceived Stress Scale scores was explored. For this analysis, the Autism group consisted of 75 children with Autism;

and the other group consisted of 46 children with other Pervasive Developmental Disorders (PDD-NOS, and Asperger's disorder). The difference between the two groups based on current stress as reflected by the Perceived Stress Scale scores was also not significant [$F(1, 119) = 0.06, p = 0.81, \text{partial eta-squared} = 0.00, \text{power} = 0.05$].

Type of Diagnosis and Parent Satisfaction with Services

It may be possible that parents in the Autistic group would report more stress and less satisfaction than parents in the other group due to the relative severity of symptoms. However, it may also be possible that because it is difficult to differentiate between the subtypes of autism, children in the other group may not be diagnosed until later and as a result parents may experience difficulty obtaining a diagnosis. This may lead the other group to experience more stress and less satisfaction with services than the Autistic group. Therefore, the direction of this hypothesis could not be predicted.

The difference between the two groups based on the parental level of overall satisfaction with current services was not significant [$F(1, 120) = 1.27, p = 0.26, \text{partial eta-squared} = 0.01, \text{power} = 0.20$]. The diagnostic groups were compared based on the level of parent satisfaction with each of the intervention services (namely speech therapy at school, private speech therapy, occupational therapy at school, private occupational therapy, special education at school, behavior therapy at home, and other services).

Separate one-way ANOVAs were conducted for each of the services received. The two diagnostic groups differed significantly from each other based on the level of satisfaction with speech therapy at school [$F(1, 103) = 10.24, p < 0.05, \text{partial eta-squared} = 0.09, \text{power} = 0.90$]. It was found that parents of children with other diagnoses ($M = 5.50, S.D = 1.48$) reported being more satisfied with speech therapy at school than

the parents of children with autistic disorder ($M = 4.79, S.D = 1.78$). The two diagnostic groups differed significantly from each other based on the level of satisfaction with special education at school was also significant [$F(1, 100) = 8.83, p < 0.05$, partial eta-squared = 0.08, power = 0.83]. It was found that parents of children with other diagnoses ($M = 5.78, S.D = 1.37$) reported being more satisfied with special education at school than the parents of children with autistic disorder ($M = 4.85, S.D = 1.61$).

The two diagnostic groups were not significantly different from each other based on the level of parent satisfaction with each of the therapies: private speech therapy [$F(1, 57) = .29, p = 0.58$, partial eta-squared = 0.00, power = 0.08]; occupational therapy at school [$F(1, 100) = 1.06, p = 0.30$, partial eta-squared = 0.01, power = 0.17]; private occupational therapy [$F(1, 49) = 0.11, p = 0.74$, partial eta-squared = 0.00, power = 0.06]; behavior therapy at home [$F(1, 643) = 1.90, p = 0.17$, partial eta-squared = 0.02, power = 0.27]; and other services [$F(1, 54) = 0.05, p = 0.81$, partial eta-squared = 0.00, power = 0.05].

Exploratory analysis

Furthermore, exploratory analyses were conducted on some of the variables. These are described in the section below. Since these analyses were done only for exploratory purposes, we hoped to find some significant findings rather than control for Type 1 error. Therefore the alpha levels were not adjusted.

First, the diagnostic groups (Autistic, Asperger's, and PDD-NOS groups) were compared with each other based on the age of diagnosis (dependent variable), using separate one-way ANOVA. The Autistic group consisted of 76 children with Autistic disorder; the Asperger's group consisted of 11 children with Asperger's disorder, and the

PDD-NOS group consisted of 34 children with PDD-NOS. Since there were only two children in the Childhood Disintegrative Disorder group, it was dropped from the analysis.

It was found that the diagnostic groups differed from each other significantly based on the age of diagnosis [$F(1, 118) = 6.59, p < 0.05$, partial eta-squared = 0.10, power = 0.90]. The simple contrasts yielded two models: Autistic versus the Asperger's group; & Autistic group versus the PDD-NOS group. The simple contrast between the Autistic group and the Asperger's group were significant based on the age of diagnosis [$F(2, 118) = 1.39, p = 0.00$, partial eta-squared = 0.10, power = 0.90]. Thus it was found that the age at which diagnosis is received is earlier for the Autistic group ($M = 2.81, S.D = 1.10$) than the Asperger's group ($M = 4.20, S.D = 1.89$). Furthermore, the simple contrast between the Autistic group ($M = 2.81, S.D = 1.10$) and the PDD-NOS group ($M = 3.28, S.D = 1.31$) revealed no significant difference [$F(2, 118) = 0.46, p = 0.07$, partial eta-squared = 0.10, power = 0.90]. However, it showed some trend towards significance.

It was examined if the parents grouped according to time spent by professionals on each of the following variables: discussing the diagnosis of their child; discussing the initial reactions of parents; and discussing the possibilities of seeking interventions; differed from each other based on parent stress experienced at diagnosis. It was found that the parent groups according to time spent by the professional on discussing the initial reactions of parents based on the parent stress scores was significant [$F(3, 88) = 4.17, p < 0.05$, partial eta-squared = 0.12, power = 0.83]. Furthermore, simple contrasts were performed on these variables. It was found that the parents who reported that the professional spent 1 full session ($M = 4.07, S.D. = 2.12$) differed significantly from those

who reported the professional spending less than half a session ($M = 5.53, S.D. = 1.73$) with them based on the stress scores [$F(3, 88) = 1.46, p < 0.05$]. The group with whom professional spent half a session ($M = 5.28, S.D. = 1.84$) differed significantly from the group with whom the professional spent 1 full session ($M = 4.07, S.D. = 2.12$) based on their stress scores [$F(3, 88) = 1.21, p < 0.05$]. Finally, the group with whom professionals spent more than half a session ($M = 6.83, S.D. = 0.40$) also differed significantly from the group with whom the professional spent 1 full session ($M = 4.07, S.D. = 2.12$) based on their stress scores [$F(3, 88) = 2.76, p < 0.05$].

Furthermore, it was found that the parent groups according to time spent by the professional on discussing the diagnosis based on the parent stress scores was not significant [$F(3, 117) = 0.61, p = 0.60, \text{partial eta-squared} = 0.01, \text{power} = 0.17$]. The parent groups according to time spent by the professional on discussing the possibility of seeking interventions was also not significant [$F(3, 93) = 0.40, p = 0.75, \text{partial eta-squared} = 0.01, \text{power} = 0.12$].

. Finally, the link between overall parent satisfaction with current services and the progress that the child has made till now was explored. Overall parent satisfaction with current services was measured on a 7-point Likert scale (1 = Not at all satisfied, and 7 = fully satisfied). The parent reports of progress that the child has made till now was also measured on a 7-point Likert scale (1 = No progress; 7 = Excellent progress). The correlation between the parent reports of progress that the child has made and the overall satisfaction with current services was significant (Pearson $r = 0.35, p < 0.05$).

CHAPTER VI

DISCUSSION

Ages of First Concerns, Referral, Diagnosis and Intervention

Results of this study indicate that the diagnosis of autism is being received at an earlier age (3 years) in United States than that reported in the United Kingdom population (6 years) in the Howlin and Moore study (1997) and the Smith et al. (1994) study. It was clear from the results that the majority of the children (90%) in the current study were diagnosed before the age of 5 years, 75% of whom were diagnosed before the age of 3 years. The mean age at which children received services after the diagnosis was 2.83 years (*S.D.* = 1.34, range = 0-7.3). This is a little earlier than the average age of diagnosis suggesting that some children may have received services even before they were formally diagnosed.

The proposition that some children may have received services before the diagnosis may be strengthened by the information that the average age at which parents first noticed concerns was 1.48 years with the range being from birth to 4 1/2 years. The average age when children were referred for evaluation was 2.45 years, with a wide range of 0 -7 years. This indicates that while a few (4%) children were referred at birth, some (14%) were referred from ages 3 to 7 years. Overall a pattern emerged that the majority of the parents become concerned before the age of 2 years, are referred for an evaluation by age 3, and are diagnosed before the age of 5 years.

Parent Characteristics

While it was evident that on an average, parents had to wait for 6 months to get a diagnosis after they were first concerned, some parents did not have any delay in getting a diagnosis after they were first concerned. One possible explanation for this may be that the parents in this sample were well-informed and receptive about their child's problems. This may be confirmed by the fact that majority (90.5%) of the parents reported that they noticed first concerns, and 15% reported that they referred their child for an evaluation. This is consistent with the Smith et al (1994) study which reported that 87% of the parents reported that they noticed concerns first.

Additionally, parents reported using more solution-focused strategies such as contacting the professionals immediately, searching the web for more information, joining autism support groups, reading books and following recommendations from the books. It should also be noted that about 80% of the parents used the internet to collect information about the diagnosis. It may be deduced that this sample consisted of families who had access to the internet and were internet savvy, and as a result kept themselves updated about the latest information about the field.

It is impressive that most of the parents sought help within a week of getting a diagnosis. In fact some parents reported that they had already been receiving services even before the diagnosis and continued with them thereafter. In the Howlin and Moore (1997) study, parents tended to wait another 6-7 months before actively seeking help. This leads us to think that either the parents in the current study were a unique group based on their proactive nature, or it might be possible that general awareness amongst the public about autism has increased along with improvements in accessibility to

services, thus leading parents to seek help early. Early identification of developmental disorders, including autism, has become a “best practice” since it helps families gather information and begin treatment early (Filipek et al., 1999).

The majority of parents coped with the diagnosis of autism through social support from family, friends and parent support groups. Moreover, 77% of the parents reported being affiliated to an autism organization, parent group or a parent network. Research has shown that social support in families with disabilities is significantly related to child behavior characteristics which in turn are significantly related to child progress (Kazak & Marvin, 1984). Additionally, having a social support system (consisting of a spouse, significant other, or a parent support group) for a parent, is critical in caregiver health, and subsequently, impacts the way in which a caregiver interacts and participates in his/her child's treatment (Brofenbrenner, 1979). Further research suggests that when parents and caregivers are actively involved in their autistic child's programming and training, the prognosis is significantly better for both parent and child (Koegel, Schreibman, O'Neil, & Burke, 1983).

Overall, the parents in this sample were well-educated (67% of the parents had a college degree or higher), were well-off (77% of the families had an annual household income of \$40,000 and above) and had a strong social support (77 % were affiliated to an autism organization, parent group or a parent network, 61% sought support from family, and 39% sought support from friends) which may have affected the early diagnosis and early intervention for their children. It may be argued that in this sample, early identification and intervention may have affected the progress that their child had made up till now, which most of the parents reported to be moderate to excellent. Research

suggests that starting intervention at a young age is associated with a positive impact on later functioning, as is evident by improvement in language, IQ and behavior (Bondy & Frost, 1995; Harris & Handleman, 2000; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Ozonoff & Cathcart, 1998; Rogers, 1998).

Resources Spent on Diagnosis and Intervention

The average amount of money spent by parents on diagnosis was \$ 759. It was interesting that almost 65% of the parents spent nothing or less than \$ 100 on the diagnosis. This is comparable to 60% of the parents who spent none or less than \$100 on current intervention. Although a majority of parents (77%) in this sample had an annual household income of \$40,000 and above, 23.4% reported their income to be below \$40,000 and 23.4% reported their income to be equal to or greater than \$100,000.

However, socioeconomic status of the parents should be considered relative to the area of the country where they reside and the associated cost of living. Thus, two possibilities arise with the groups of parents on both ends of the spectrum. It may be possible that parents, who were on the middle to higher end of the spectrum of household income, may have had adequate insurance plans to cover the expenses of their services. The other possibility is that parents on the lower end of the spectrum may not have had good insurance plans to support services for their child. They may have taken advantage of the National Health Plans such as Medicaid to pay for their child's treatment. While some parents (55.6%) reported their children were receiving school-based services, others (32%) reported receiving state-funded services. This may be another reason why most of the parents in this sample may have spent nothing or less than \$100 on diagnosis and interventions.

When asked about how much time they spent on intervention services, half the parents reported that they spent 10-40 hours on intervention every week. Even though spending 10-40 hours may seem more than sufficient for children in general, it may not be adequate for children with autism given the research about remarkable gains after intensive behavioral interventions (Lovaas, 1987). Only 3% of the parents noted that they spent more than 40 hours a week on intervention. When asked about their opinion about whether their children should receive 40-hours of therapy every week, 45.2% disagreed, 40.5% agreed and the remaining parents were neutral.

The above findings suggest several possibilities. First, even though some parents may wish to provide 40 hours of therapy, they may not have time to provide intensive behavioral treatment. Second, it may be possible that children may be receiving 40 hours of therapy per week across home and school/private settings. However, since the question only sought to ask about the time spent by parents on intervention, the number of hours reported may not be the total number of hours of therapy that their children receive per week. Third, some parents may not feel that their children need intensive behavioral treatment (more than 40 hours of therapy per week) because their children may be high functioning and making progress even with less than 40 hours of therapy.

Issues of Assessment and Diagnosis

The majority (61%) of the children in the sample were diagnosed as having Autistic disorder, followed by some (28.6%) who were diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Very few (8.7%) were diagnosed with Asperger's disorder and even fewer (1.6%) with Childhood Disintegrative Disorder (CDD).

Autistic disorder is characterized by delays or abnormal functioning in at least one of the following areas prior to age 3 years: social interaction, language as used in social communication, or symbolic or imaginative play (DSM -IV-TR; American Psychiatric Association, 2000). In this sample, some parents (35%) reported worrying about the child before the age of 1 year. According to DSM-IV-TR, the manifestations of autistic disorder in infancy are more subtle and difficult to define than those seen after 2 years. Therefore, it could be argued that since 84% of the parents (of whom 41% were concerned before the age of 1 year) reported being worried before the age of 2 years; the problems were severe enough to be concerned that early. The severity of the problems may be evident in the fact that parents reported noticing transition difficulties (44.4%), solitary play (41.3%), lack of eye contact (36.5%), and developmental delays (32.5%) before the age of 1 year. As a result, these children may have received the diagnosis earlier than the children with other diagnoses under the umbrella of Pervasive Developmental Disorders. This may be confirmed by the results of the exploratory analysis, that the group with Autistic disorder ($M = 2.81$ years) was diagnosed earlier than the group with Asperger's disorder ($M = 4.20$ years). Although there were no significant differences in the age of diagnosis of the Autistic group ($M = 2.81$ years) and the PDD-NOS group ($M = 3.28$ years), there was a trend towards significance suggesting that it may be worthwhile to explore further.

In children with Asperger's disorder, there are no clinically significant delays or deviances in language acquisition before the age of 3 years, in contrast to children with Autistic disorder. Although these children are usually described as using "adult-like" language, they may have difficulties in communication due to social dysfunction (e.g.

failure to identify non-verbal cues, and failure to appreciate the rules of conversations). Parents may not be concerned about their child until the child begins pre-school or is exposed to same-age children, at which point their social skill deficits may become apparent. In most of the school-age children with Asperger's disorder, good verbal abilities may mask the severity of social dysfunction. This may mislead parents to focus on the child's good verbal abilities, while being insufficiently unaware of the deficits in the social aspects of language development. This may suggest that parents may not be concerned about their child until later, thus receiving a diagnosis at a later age than the other diagnosis. This was partly supported by the results that children with Asperger's ($M = 4.20$ years) received their diagnosis significantly later than children with Autistic disorder ($M = 2.81$ years).

Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS) is the category used when there is a severe and pervasive impairment in the development of reciprocal and social interaction associated with impairment in either verbal or non-verbal communication skills or with the presence of stereotyped behaviors, interests, and activities, but criteria are not met for a specific Pervasive Developmental Disorder (DSM-IV-TR).

In review of literature, Towbin (2005) listed situations in which a diagnosis of PDD-NOS is given. First, it was found that this label is often used as a "default" diagnosis when inadequate information about the symptom presentation is available to make a specific diagnosis. Second, this diagnosis is given to children whose symptoms are severe enough to warrant a diagnosis on the autism spectrum, but do not meet criteria for Autistic disorder. Third, PDD-NOS is diagnosed in children who have a late age of onset

(i.e. after the age of 3 years) of symptoms of autism and early onset of impaired reciprocal social relationships.

Based on the third situation as listed by Towbin (1997), it may be argued that if a child presents with stereotyped behaviors or activities and no language deficits, he/she may be initially diagnosed with PDD-NOS. When the child's social skill deficits become apparent at about the time that he/she goes to pre-school, he/she may meet criteria for a diagnosis of Asperger's disorder. The diagnostic criteria as listed by the DSM-IV-TR, present a challenge in the differential diagnosis of Asperger's disorder and PDD-NOS. Furthermore, currently there are no diagnostic instruments to differentiate between PDD-NOS and Asperger's disorder. Therefore, it may be argued that given the ambiguity of the use of diagnosis of PDD-NOS, children who are later diagnosed with Asperger's disorder (around 4-5 years) may be initially diagnosed with PDD-NOS (around 2-3 years). Therefore, it is proposed that the number of children with PDD-NOS (N = 35) in this sample may have been currently misdiagnosed and overrepresented.

The first concerns that the parents noticed were speech delays and insufficient amount of speech. This is consistent with the fact that a larger portion of our sample (61%) was diagnosed as having Autistic Disorder. In contrast to Autistic disorder, there are no clinically significant delays in early language in Asperger's disorder (DSM-IV-TR). A relatively lower percentage of the sample was diagnosed with Asperger's disorder and therefore only a few parents were first concerned that their child was using language much higher for his/her age. This characteristic of children with Asperger's disorder distinguishes them from the children with Autistic disorder.

Very few parents noted self-injurious behaviors (2.4%), which may indicate that not many of the children had co-morbid mental retardation. Self-injurious behaviors observed in children with autism are more closely linked to the mental retardation that often accompanies autism than to autism per se (Dawson, Matson, & Cherry, 1998). Even fewer parents noticed lack of pointing (1.6%) as their first concern. Noticing lack of pointing may be especially important because joint attention (shared attention between social partners through non-verbal gestures such as pointing or eye gaze) differentiates children with autism from the typically developing or delayed children (Dawson et al., 2004; Sigman, Kasari, Kwon, & Yirmiya, 1992). Some aspects of joint attention typically emerge by 9–12 months of age (Brooks & Meltzoff, 2002), with some aspects emerging as early as 6 months of age (Morales, Mundy, & Rojas, 1998). By 12 months of age, most typical infants display all aspects of joint attention, including sharing attention (e.g., through the use of alternating eye gaze), following the attention of another (e.g., following eye gaze or a point; Toth, Munson, Meltzoff & Dawson, 2006). Thus, it may be important for parents to understand that pointing is a critical skill that most children should develop before the age of 1 year, in order to have a successful speech and language development. Therefore, even before parents can detect speech problems, it may be possible that parents can detect deficits in joint attention skills as early as 6 months and thus may lead to even earlier diagnosis.

When asked about the personnel who referred their child for a diagnostic evaluation, some (15%) parents reported referring their child on their own. Some (46%) reported being referred by a pediatrician and some (15.9%) by a primary care physician. Very few reported that a teacher, school psychologist or day care personnel referred the child. It is

impressive to find that a substantial number of children were referred for further testing by a pediatrician and only 15% of the parents referred their own child. In the Howlin and Moore (1997) study, about 10 % of the parents reported that although a cause for concern was acknowledged, some were told to return if problems persisted; while others were reassured that their children will “outgrow” their problems. In the current study, only 1.6% of the parents were told not to worry and reassured that their children will outgrow their problems. This suggests that professionals are being aware of symptoms of autism and rather than overlooking parents’ concerns, they are taking active steps towards early diagnosis and intervention.

The Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview - Revised (ADI-R) are considered to be the 'gold standard' in diagnostic evaluations for autism (Reaven, Hepburn & Ross, 2008). However, it was evident from the current study that only 26.2% of the parents reported using the ADOS, and 13.5% reported using the ADI-R. It may have been possible that parents did not know the type of tool that was used to diagnose their child (31.7%). Furthermore, professionals who diagnosed most of the children were clinical child psychologists (35.7%), pediatricians (18.3%), and a specialty clinic or a team of professionals (15.9%). Very few mentioned that psychiatrist, school psychologist, state department case worker, primary care physician, neurologist, infant developmental specialist, neuropsychologist, and speech therapist diagnosed their children for the first time. Professionals who are qualified to use the ADOS and ADI-R are those who have education, training and experience in using individually administered test batteries and who have a background and experience in the treatment of autism (Lord, Rutter, DiLavore, & Risi, 2000). Some examples of clinicians

who have a professional mandate to treat autism and who make use of the ADOS in their daily work are clinical and school psychologists, psychiatrists, occupational therapists, and speech and hearing professionals (Lord, Rutter, DiLavore, & Risi, 2000). From this, it is evident that others who diagnosed the children may have used brief observations during office visits, clinical judgment, and general awareness about autism and parent reports to diagnose autism.

Several issues in relation to the diagnostic instruments and the professionals making the diagnosis arise. First, results suggest that these instruments, in spite of being the “gold standard” for autism assessment, are not being used commonly. It may be possible that since this is an expensive tool, professionals may be using other less reliable but inexpensive tools (such as parent reports, clinical judgment and experience) which may give them an idea about the clinical picture of the child. For example, a pediatrician may spend only about 10-15 minutes talking to the parent about their concerns and they may diagnose a child just based on the parent reports. This is compared to a professional who uses standardized assessments and diagnoses a child based on the information from multiple informants, results of the standardized assessments, and clinical judgment. This leads us to the second issue that inconsistency in diagnostic procedures of children with autism across professionals becomes apparent. Therefore, it may be possible that a child receives a particular diagnosis depending on the professional who diagnosed him and the assessment measure used. The third issue concerns the challenges of differential diagnosis of Pervasive Developmental Disorders. Currently none of the diagnostic tests available can reliably differentiate among Autistic disorder, PDD-NOS and Asperger’s

disorder; children often receive several different labels falling under the pervasive developmental disorder umbrella.

In addition to the autism-specific tests, parents also reported using other diagnostic tests such as a variety of behavior rating scales, adaptive behavior scales, developmental tests, language tests and standardized cognitive tests. These other tests may be used to evaluate other behavior problems, language and adaptive skills for program planning purposes. These tests are directed more narrowly at behavior in specific areas (e.g., language scores from the language tests, high activity scores from the behavior scales) and thus may be more sensitive to change than are behaviors associated with actual diagnostic criteria as seen on the ADOS (Lord, Rutter, DiLavore, & Risi, 2000). Therefore, in the current study, these tests may have been used to track development rather than for diagnosing autism per se. However, the cognitive tests may have been used to differentiate between mental retardation and autism. It has been found that individuals with autism tend to display a specific pattern of cognitive abilities, performing better on non-verbal visual-spatial tasks than on the verbal tasks, thus scoring better on the performance subtests than on the verbal subtests (Happé, 1994). These diagnostic and testing issues impact the accuracy of diagnosis, and thus need to be further explored.

Parent Stress at Diagnosis

Almost 85% parents placed their stress levels on the continuum from moderately stressed to extremely stressed. Only 4.8% reported that they were not at all stressed. Furthermore, the possible correlates of parent stress at diagnosis were explored. These were the level of difficulty obtaining a diagnosis, and the child's age at diagnosis. The

link between the stress that parents experienced after obtaining a diagnosis and the level of difficulty obtaining a diagnosis was not significant. This suggests that even though parents experienced difficulty obtaining a diagnosis, they may not have experienced significant stress at the time of diagnosis. This did not support our hypothesis that these two variables would be significantly correlated.

Some possible explanations for the above results are proposed. Stress that parents experienced was reported retrospectively. Inaccuracy of retrospective coping accounts might result from several factors. Research suggests that individuals bias their recall of events to maintain unrealistically positive self-views (Ptacek, Smith, Ronald & Espe, 1994). One may be passage of time, which may result in distortion through retroactive inhibition produced by intervening events (Ebbinghaus, 1964). Recall may also be interrupted by the outcome of the coping process. For example, in this study, if parents experienced a positive outcome after the diagnosis, they may have been motivated to disregard the stress that they experienced and thus selectively recall only the positive coping process. Thus, it may be possible that the nature of services that they received may have undervalued the stress that they experienced. Thus, this shows that the results obtained from retrospective reporting may need to be used with caution.

Next, the link between the child age of diagnosis and stress at diagnosis was not significant. The direction of the hypothesis about the correlation between child age of diagnosis and parent stress at diagnosis was not specified because two ways of explaining the link exist. If the child is diagnosed earlier, then parents may experience less stress as a result of improvements in child's behaviors due to early intervention. However, if the child is diagnosed earlier, it may be possible that the child has severe deficits to warrant

an early diagnosis. Since there is no link between the two variables, it may be possible that both of the above explanations are still applicable.

Another possibility is that parents may have been more stressed when they first noticed concerns. By the time they received the diagnosis, they may have been accustomed to the diagnosis. This may be supported by research that parents accept their child after being in shock and denial (Blacher, 1984). By this time, they may have channeled their energies to problem solve and think about the future of their child. However, at this point they may encounter other issues from concerns about financial and psychological support for their child throughout his or her life, to concerns about obtaining the best available treatment services for the child. Therefore, it is evident that parents may be experiencing stress at different points in the diagnostic timeline, but this stress may stem from different issues. This explains the pervasiveness of stress during the diagnostic and treatment process.

Most of the parents were concerned about getting services for their child and being able to provide financial assistance. This may be reflected in the fact that a majority of the parents reported that they coped with the diagnosis by looking for services immediately after the diagnosis. It is possible that some parents may have felt guilty to think about negative feelings, as a result may have disregarded them, thus channeling them into positive outcomes. These feelings of guilt may lead parents to feel less competent in the parenting role (Kuhn and Carter, 2006). Furthermore, guilt may stem from the old belief in which mothers were blamed for their children's autism disorder (e.g., Bettelheim, 1967) and may contribute to the social stigma some mothers feel.

However parents' perceptions of the causes of autism for their child revealed that only a few (4%) mothers endorsed their own behavior as a cause for their child's autism.

While many parents (65%) reported that they felt relieved to get a diagnosis, some (35.2%) reported feeling depressed. One commonly held assumption is that the multiple stressors associated with being a parent of a child with a disability could result in higher rates of depression or depressive symptoms, especially for mothers (Bailey, Golden, & Roberts, 2007). Only a few parents endorsed negative feelings (such as feeling mad, depressed, and stressed) after getting the diagnosis. This may be possible that these few parents may have expected a diagnosis other than autism and as a result may have been distressed. Parents who suspect the diagnosis of autism may have positive reactions like relief, acceptance of the diagnosis, and receptiveness to additional information, whereas, parents who suspect a problem other than autism may have mixed positive as well as negative feelings including relief, receptiveness, denial, anger and devastation (Nissenbaum, Tollefson & Reese, 2002).

Parents' Perception About the Causes of Autism

Parents' perceptions about the causes of autism for their child revealed that 44% of the parents endorsed vaccinations as a possible cause of autism. This suggests that, in spite of the widespread awareness that is being created by the public health community that vaccines do not cause autism, some parents still believe that they do. The parents in the current study may be similar to other parents who strongly believe that the Measles/Mumps/ Rubella (MMR) vaccine causes their children's autism. Because the symptoms of autism begin to occur around the same time as the child's MMR vaccination (around 18 months), parents consider this vaccine as the cause of the autism. These

parents' beliefs and observations originated from the first media coverage which was a result of a small study of gastrointestinal disease and autism, published by Wakefield and his colleagues in 1998. It was suggested in the study that there was a link between the MMR vaccine and autism. However, many subsequent studies have refuted these findings (Taylor, Lingam, & Simmons, 2002; McGregor et al, 2000).

The recent publicity of court cases and parent advocacy groups may have influenced parents' beliefs resulting in the persistence of the debate inspite of the controlled studies. Despite the lack of scientific evidence of a link between thimerosal and autism, a number of public health organizations and vaccine manufacturers eliminated thimerosal from vaccines as a precautionary measure. However, a recent study has failed to support this hypothesis. (Schechter & Grether, 2008)

Despite experts and health organizations refuting this theory of a connection between vaccines and autism, recent events have brought the debate in the news once again. One of the major implications of the press continuing to cover this debate is that many parents may not get their children vaccinated against common childhood diseases, such as measles, mumps and rubella. These preventable diseases can lead to death or severe impairments in children. Thus, it is apparent that media coverage of the vaccine debate may have other detrimental effects, such as falsely leading parents to believe that there may be a cure for autism. Furthermore, the internet can influence perceptions about vaccines because it is the fastest growing source of consumer health information. With rapidly increasing use of the Internet as a health information source, the general public may accept these claims and refuse vaccination of their children (Zimmerman, Wolfe, & Fox, 2005).

Parents in the current study reported additional causes: genetic and chromosomal factors (62%), abnormalities in the brain (33.3%); and prenatal and perinatal factors (23%). Several studies have shown promising results to show that autism may be a genetic disorder (Xi, Ma, & Lu, 2007; Vourc'h, Martin, Bonnet-Brilhault, 2003; Hettinger, Liu, & Holden, 2008). Concordance rates for autism in monozygotic twins range from 36%-91% (Bailey, et al., 1995); whereas dizygotic twins show the same concordance rates as the siblings. It was interesting to see that inspite of the media coverage on vaccination debate; many parents also believed that there may have been a genetic cause for their child's autism. This suggests that the parents in this sample were willing to consider other options, or were well-updated with the latest knowledge in the field. However, since this question was a multiple choice question and parents could check more than one option, it may be hard to tell whether parents believed in one particular cause stronger than the other one. Parents may have checked all the possible universally known causes, not thinking about their own opinion per se.

Many studies have consistently reported that individuals with autism may have high levels of serotonin in their brains which cause aggression and stereotyped behaviors (Anderson et al, 1987). Another neurobiological theory that is proposed is that, there is damage to the amygdala and the frontal cortex in children with autism, which contributes highly to social impairment (Schultz & Anderson, 2005). The results of studies with birth complications in children have not pointed to any factors that strongly associated with autism. In one study with a sample of high-functioning cases of autism, it was found that only one factor (gestation period of more than 42 weeks) differed between people with autism and their siblings (Lord, et al., 1991). Thus, there are numerous theories of autism

proposed in research which have scientific evidence. As professionals, it is critical that we keep our minds open and consider various hypotheses in the causation of autism, and accept only those that have scientific evidence.

Issues About Interventions

Although there is still no cure for autism, considerable progress has been made in the treatment of autism. Various programs have proven to be effective in increasing the quality of life of children with autism. Early psychodynamic oriented approaches such as “Parent-ectomies” (Bettelheim, 1967) involved cutting children off from their parents. This approach has replaced other approaches (TEACHH, Denver Model, and Lovaas) in which parents are at the helm of their children’s treatments. The Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) program involves focusing on development of an individualized program based on the autistic child’s skills, interests, and needs. Structured teaching is the primary basis of this approach (Marcus, Schopler and Lord, 2001). Parents serve as co-therapists and implement this approach successfully in home settings causing significant gains in child behavior (Ozonoff & Cathcart, 1998; Short, 1984).

The Denver Model is a comprehensive interdisciplinary approach which can be implemented in various treatment settings namely a center-based model, within family routines, at the preschool and in a one-to-one interaction. This model emphasizes play, language, cognition and social relations. It has been found to significantly increase social communicative play skills, social interaction with various partners, and thus result in tremendous progress in cognition, language and perceptual fine motor areas (Rogers et al, 1986).

The Lovaas method or discrete trial training is based on the principles of behavior modification and grew out of the work of Ivar Lovaas (1987). It is built on the operant conditioning principles and consists of breaking down tasks into small components and constantly providing one-to-one teaching with primary reinforcers such as food. Lovaas claims that with intensive treatment (about 30-40 hours per week) at an early age, children can gain skills to such an extent that they no longer exhibit symptoms to warrant a diagnosis of autism. This suggested that he claimed to “cure” autism through his technique. The Lovaas method, despite the flaws to its research, is a very popular method (Mesibov, Adams, & Klinger, 1997). The flaws noted in the Lovaas’s study (1987) were that the children who improved were high-functioning, thus limiting the external validity, and his study was not replicated by others to confirm the results (Eikeseth, 2001). Parents are desperate to seek treatments for their child and definitely so if those treatments claim to cure autism. Parents may also have been impressed by Catherine Maurice’s (1993) book on her two children with autism who “recovered” using the Lovaas approach.

The field of autism is replete with other examples where strong beliefs, rather than research-based evidence, have led to the promotion of inefficient interventions. Facilitated Communication Training is one such intervention. Facilitated communication is a process by which a facilitator supports the hand or arm of an autistic child while using a keyboard or typing device. While it has been claimed that this process enables people with autism or mental retardation to communicate, a majority of peer reviewed scientific studies have concluded that the typed language output attributed to the clients was directed or systematically determined by the therapists who provided facilitated assistance (Shane et al., 1982).

Apart from the well-researched interventions which are effective for children with autism, (59.2%) parents reported using other interventions which do not have enough research evidence to support their effectiveness. The alternative therapies reported were adaptive music, auditory training, cranio-sacral therapy, Reiki, nutritional/diet therapy, naturopathy, hippotherapy, sensory integration, and neurofeedback.

This finding was surprising given the well-informed nature of the sample as described before. However, taking into consideration that the parents in this sample used internet quite often, it may not be surprising that they were exposed to information about alternative treatments. It may be argued that frustration with current services may have driven these parents to seek alternative treatments (Levy, Mandell, & Murhar, 2003). Families with young children with autism often feel the pressure to act immediately, and not to wait for confirmatory scientific studies (Levy, & Hyman, 2005). It is also possible that parents may have chosen the alternative treatments based on anecdotal evidence that it worked for some other child. There are many anecdotal descriptions of autistic children who have responded to alternative treatment and appeared to no longer meet the diagnostic criteria for autism (Michelloti et al., 2002; Seroussi, 2000). While conventionally prescribed treatments (such as ABA, TEACHH, Denver Model, etc.) for autism spectrum disorders address the symptoms of autism; complementary and alternative therapies claim to cure autism by targeting its cause (Levy, & Hyman, 2005).

It may also be possible that parents who focus on environmental toxins, because of overexposure of that possibility through the media, may be less likely to seek behavioral treatments, like applied behavior analysis, which has shown promise in scientific studies. In order to educate parents about choosing the right therapy for their child, professionals

may need to spend time with the parents regarding the effective treatments for their child. Also, clinicians need to be aware of the interventions that families use in order to be able to assist in supporting the family and monitoring the child for side effects (Levy, & Hyman, 2005).

Time Spent by Professional

A large number of parents (67%) thought that it would have been helpful if the professional making the diagnosis would have spent time in discussing the prognosis and the future recommendations for their child. From the data, it was evident that although professionals spent time in discussing the diagnosis with parents, they spent relatively lesser time on discussing parents' reactions and even lesser time discussing the treatment recommendations.

In the current study, the differences between the groups of parents (according to the time spent by the professional on discussing initial reactions) based on stress scores, was significant. Specifically, the groups with which professional spent 1 full session discussing their initial reactions experienced significantly lower stress than the group with whom the professional spent less than half a session. Although it may be inferred from the results that professionals spent less time discussing the parents' reactions, it may also be possible that professionals may not have been able to discuss parents' reactions because parents may have been highly stressed. This finding needs to be confirmed further.

Current Stress

The mean PASS score is consistent with the mean of the normative clinical sample (Berry and Jones, 1995). The mean PESS score falls in the middle of the range of

possible scores (0-40). It is evident that the parents in this sample reported experiencing moderate to elevated levels of current stress. Even though parents appear to be adopting a proactive approach in coping, and report that they felt relieved after getting the diagnosis, it is evident that these parents continue to experience clinical levels of stress. Therefore, it is important to address this stress in a timely fashion. This implies that mental health professionals and physicians should consider assessing parent stress at the time they provide a diagnosis for the child and continue to monitor it during the treatment process as well.

Next, none of the findings in the analysis conducted to evaluate whether the diagnostic groups differed based on current parent stress were significant. First of all, it was found that the difference between the two groups (autistic group versus other group) based on current stress as reflected by the Parental Stress Scale Scores was not significant. Secondly, the difference between the two groups based on current stress as reflected by the Perceived Stress Scale scores was also not significant. This means that parent stress does not differ with the diagnosis of the child. However, previous research (Howlin and Moore, 1997) has suggested that parents with children with Asperger's disorder experience more frustration and greater delays in their search for a diagnosis than those with children with Autistic disorder.

Noh, Dumas, Wolf, & Fisman (1989) found in their study (with children with conduct disorder, autism, Down's syndrome, and normal children) that there were no significant differences between the stress scores of the normal group and the three diagnostic groups. However, the mothers of children with handicaps seemed to have more difficulties than mothers of normal children with respect to depression and sense of

competence in their parenting role. There were also indications that these mothers of children with handicaps were more likely to feel the burden of childcare demands as a result of which they felt isolated. Thus it may be worth exploring further whether the diagnostic groups differ at an item-level of the measures. Also, an attempt needs to be made in future studies to get an even number of participants in each group.

Parent Satisfaction

Even though 66% reported finding it somewhat difficult to extremely difficult to obtain diagnostic services, 60% of the parents were moderately to fully satisfied with the diagnostic services that they received. Additionally, 66.4% of the parents agreed that their child should have been diagnosed earlier. From the above information, it is not clear as to on what basis the parents made their ratings of satisfaction of services. For example, if parents had to travel to a center in a nearby city to get diagnostic services, where they may have received good services, parents may have reported being satisfied, overlooking the inconvenience that may have caused them. Therefore, it would have been helpful if this question about satisfaction with diagnostic services would have been further broken down into different aspects of the process, such as satisfaction with the services at the clinic, satisfaction with the availability of services in their area of residence, and satisfaction with the age at which their child received the diagnosis.

It was found that the current stress was not significantly correlated with parental ratings of overall satisfaction of current services. Although the direction of our hypothesis (higher the stress, lower the satisfaction) was evident, our hypothesis that current stress and satisfaction would be significantly correlated was refuted. This was contrary to our hypothesis that it would be positively correlated. Only the correlation of

Parental Stress Scale scores with parent satisfaction of other services was significant. This relationship may not be meaningful given that none of the other correlations with any of the therapies are significant. Future research may involve studying other factors that may be related to the satisfaction such as progress that the child has made up till now.

The differences between diagnostic groups based on the level of satisfaction with speech therapy at school and special education at school were significant. It was found that parents of children with other diagnoses (Asperger's and PDD-NOS) reported being more satisfied with speech therapy at school and special education at school than the parents of children with autistic disorder. One possibility is that children may have been diagnosed as having autistic disorder because of severity of symptoms. The other group consisted of Asperger's, and PDD-NOS children who present with symptoms which are less severe than those of Autistic Disorder. The prognosis of these children may be better than those with Autistic Disorder. It is possible that the other group may have made more progress, and as a result, their parents were more satisfied with the services. Parents' satisfaction of services at school may also reflect on the quality of education programs that are being provided at the schools.

Geographical Location

Participants were recruited from across 30 states in the United States, thus representing the types of services that are received in the United States. However, the geographical location was not well represented. Most of the parents were from urban location. A true rural population was not obtained.

The families living in urban versus rural areas did not differ significantly based on their stress scores. The satisfaction with current services of families living in rural areas was comparable to those living in urban areas. One explanation for this finding may be that this sample may not have represented a true rural population. The parents from rural areas (Population < 2,500; $N=7$) were combined with the urbanized cluster (Population = 2,500-50,000; $N=56$) and thus called a rural group. On the other hand, it is possible that both, the rural and urban groups are receiving satisfactory services. Although Howlin and Moore study (1997) explored the correlation between parents' satisfaction and geographical location, they did not further analyze whether the location, urban or rural, played a role in accessibility of services and thereby their satisfaction. Gething (1997) hypothesizes that parents who live in rural areas may encounter the challenges of unavailability of services in their area due to scarcity of specially trained professionals, complexity of the transportation modes to the urban settings and thus an increased expense for accessing these services. While Gething (1997) hypothesizes that this may be a concern, no published studies were discovered examining the issue directly. This suggests that further research is necessary to evaluate parent stress with respect to geographical location.

Parent Preferences of Models of Therapy

When asked about the model of therapy that they would prefer, 67.2% preferred both (therapist-child direct intervention, and parent consultative models), which showed that the parents were interested in being invested in their child's therapy. The benefits of parents as direct service providers were documented in research (Lovaas, Koegel, Simmons, & Long, 1973) which showed that the groups whose parents were trained to

carry out behavior therapy continued to improve, while children who were institutionalized regressed. This approach appears to be economical and feasible for treatment delivery (Schreibman & Koegel, 1996). In this model, parents are trained to be their child's therapists. Since parents also endorsed the therapist consultative model, parents may consult with the therapist once in two weeks for progress monitoring and ongoing training. While parents will be trained to be their child's therapist, therapists will supervise them. This appears to be an economical and effective model for parents.

Parents' suggestions of other models included therapist and peers model. Children with autism have been found to successfully learn and generalize through observation by the use of a peer modeling procedure (Pierce, Schreibman, 1995; Charlop, Schreibman, & Tryon, 1983). Another model that emerged from the parents' reports was a "social therapist," who would be responsible for helping their child apply the behavior learned in the classroom to generalize in the real world. This seemed similar to a job coach model. Even though this model has not been studied before; it may be a promising area. This may be especially because generalization of skills is extremely important for children with autism. A teacher can facilitate generalization at school across teachers, across activities, or across classrooms. A parent may be able to extend those opportunities to the real world. However, sometimes it may be difficult for a parent to take on the responsibility of providing opportunities in the social arena along with other family obligations. Therefore a "social coach," may help the child in becoming independent at a grocery store, movie theatre, restaurant etc.

Current Status of the Child

Most of the parents reported that their child has made good to excellent progress. Only a few reported minimal progress suggesting that the severity of symptoms of these children may have been higher than the rest of the sample. This is consistent with the fact that some parents who were concerned at birth may have had children with severe problems, resulting in poor prognosis. Another possibility is that they may have received poor services, even though the majority of the parents reported that they were satisfied with the services. This may suggest that parents who followed treatments which are not supported by research may have reported minimal progress of their child.

Finally, parents listed current strengths of their child. It was interesting to note that in spite of being stressed, most of the parents were able to come up with strengths for their child. While listing their child's strengths, more than half of the parents used the descriptors (affectionate, even tempered, and focused) that were provided as examples. This may have cued the parents to provide responses. Therefore, this question needs to be modified in such a way that parents can understand the question without the examples that were provided in the current version.

Strengths

Overall, various strengths of this study were evident. Participants were recruited from across 30 states. Thus it was a good representation of the services that are received in the United States.

Apart from updating the results from the Howlin & Moore (1997) study, this study sought detailed information about the experiences of parents while seeking a diagnosis and treatment services for their child with autism. The comprehensive survey used in this

study gathered information regarding the process of diagnosis including the first concerns of parents; people who were first concerned; initial reactions of parents after they were first concerned; people who referred the child for a diagnostic evaluation; diagnostic tests conducted; professionals who diagnosed the child; parents' reaction, thoughts and coping strategies during the diagnostic process; and parent perceptions of causes of autism. Other information included resources spent in terms of money and time on diagnosis and intervention; geographical location of diagnosis and intervention; time that professionals spent in discussing the diagnosis, parents' reactions to the diagnosis, and recommendations; nature and type of services received; and parent preferences about the model for intervention. Thus, this study sought to study variables which have been neglected in previous research.

It was taken into consideration that parents may have sought a second opinion diagnosis and hence information regarding that process was also sought. The possibility that parents may have changed treatment services from the first time they received them was also considered. Hence in addition to the information about immediate post diagnostic services, information about current intervention services were also sought. The survey consisted of both open- as well as close ended questions which enabled parents to express any additional issues that the researchers had overlooked. Another unique feature of this study was that along with the information regarding parents' challenging experiences with seeking services, information regarding positive characteristics such as the child's strengths, and progress made since diagnosis was also gathered. It was apparent that this was the only study in the United States to include the above mentioned variables.

Furthermore, retrospective (i.e. at the time of diagnosis) as well as current parent stress were measured. Two standardized stress measures were used which measured both, general stress and parenting stress. Thus, the possibility of other stressful events in the parents' life confounding the study was eliminated. It was found that the effects of diagnosis (autism group versus other group) on current stress and satisfaction of services received were not significant.

Limitations and Weaknesses

Along with the strengths, this study also had several limitations and weaknesses. Even though the parents in this study were from all over the United States, the families from ethnic minorities were not well-represented. Also, most of these parents were well-educated and thus had the financial resources to seek early diagnosis and intervention. Furthermore, the geographical location of the sample was not well represented. Since 76% of the sample were obtained from an online network of parents, it may be possible that the majority of parents who participated in the study were those who have the internet and are internet savvy. Since these families were affiliated to the online network for autism, it might have been a unique sample, thus not representing parents of children with autism who are not affiliated to support groups and networks. Very few parents were from rural areas (population less than 2500), thus limiting the extent to which we can generalize results to families from rural areas. It may be helpful to look at a true rural sample and families with less education, lower income, and not connected to online networks.

On the question about strengths of the child, parents used the descriptors that were provided as examples in the survey. This may have cued parents to provide the responses.

Therefore, this question needs to be modified in such a way that parents can understand the question without the examples provided.

Inconsistent responding was evident on the section regarding second diagnosis. It may have been possible that parents did not comprehend the question well. Thus, in order to obtain accurate information about the second diagnosis, the questions need to be clearer. Therefore the results on the second opinion diagnosis may be interpreted with caution.

Although the use of retrospective reports along with the current measures of stress was one of the strengths of the study, it may also have limited the accuracy of information recalled from a past event. There may be substantial differences between the thoughts and behaviors used during a stressful episode and a person's recollection of how he or she coped way past the event. Inaccuracy of retrospective coping accounts might result from passage of time resulting in distortion through intervening events. Coping recall may also be biased by the outcome of the coping process. For example, in this study, if parents experienced a positive outcome after the diagnosis, they may have been motivated to disregard the stress that they experienced and thus selectively recall only the positive coping process. Thus, this shows that results obtained from retrospective reporting may need to be used with caution.

Clinical Implications

Overall, it was evident from this study that the diagnosis and intervention are being received at earlier age than before. However, parents continue to experience clinical levels of stress way past the diagnosis, suggesting pervasiveness of stress through the entire process of treatment with their child. Furthermore, this stress may be exacerbated

by the fact that professionals do not spend time discussing parents' emotional reactions and coping strategies. Thus, it is clear from the study that parent awareness programs need to be created. It is important for parents to understand that pointing is a critical skill that most children should develop before the age of 1 year, in order to have a successful speech and language development. Therefore, even before parents can detect speech problems, it may be possible that parents can detect deficits in joint attention skills as early as 6 months and thus may lead to even earlier diagnosis. Thus parents need to be educated about the early signs and symptoms of autism.

Although early diagnosis and intervention are being followed, some gaps still remain. Ideas for facilitating early detection and diagnosis are proposed. First, along with parents, professionals such as pediatricians, primary care physicians, nurses, day care personnel and state health department officials need to be trained to screen for autism symptoms. Pediatricians may need to screen babies at every well-baby visits. This will ensure early diagnosis and screening. Second, professionals will need to monitor parent stress that is experienced when their child is diagnosed.

Parents may also need to be educated about the stress that they experience and the clinicians may need to point to them the difference between normal stress and clinical levels of stress, which many parents may not recognize.

It was evident that a substantial number of parents are following unconventional therapies. Parents need to be educated about the well-researched intervention strategies for children with autism. It is apparent that although there is general agreement about the importance of early intervention in autism, a question still remains about the amount, and intensity of these interventions, which may be further explored.

Furthermore, professionals diagnosing children with autism should spend time with the family discussing the meaning and implications of the diagnosis, coping strategies, and the future recommendations for treatments. This may alleviate some of the parent stress at the time of diagnosis. It is also critical that this parent stress is monitored every time the family visits the clinician. General problem-solving skills can be taught to parents to cope with the ongoing stress. Professionals may also need to teach parents to recognize clinical levels of stress for which they should be encouraged to seek help. Parents may also benefit from talking to professionals about the treatments that have been supported by research and are effective in treating autism. Thus, parent- and family-based interventions designed to support parental well-being and focusing on parenting cognitions may enhance parenting self-efficacy. Future research can evaluate the effectiveness of such programs in alleviating parent stress.

Directions for Future Research

In order to make progress in the field of autism, we need to continue to conduct research vigorously. For that purpose, it is important to rectify mistakes that have been previously conducted and formulate new ideas for research. Therefore ideas for future research are proposed.

Retrospective reporting of stress at diagnosis may be further explored. In order to evaluate the level of stress that parents experienced at diagnosis, they may be provided a specific time (e.g. 1st birthday, 1st Christmas, etc.) to refer to while recalling how they felt when he was diagnosed. Retrospective assessment of early-life stress is controversial and currently a topic of much consideration among researchers. Unless biological data (e.g. vitals signs, evidence of autonomic nervous system arousal, and acute Cortisol release)

are available at the time of exposure to a stressor, investigators must rely on parents' perceptions and reports of how much stress they experienced.

Other specific measures of stress such as Parenting Stress Index (PSI) may be used in future studies. The Parenting Stress Index yields 3 scores: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. Thus it is evident that this is a more specific measure than the measures used in the current study and will also measure both general as well as specific stress. It may be worthwhile to evaluate the predictive validity of the current stress measures with the Parenting Stress Index.

Diagnostic and assessment issues in the field need to be addressed. Given the challenges of differential diagnosis between PDD-NOS and Asperger's disorder, it may be helpful to consider modifying the DSM-IV criteria for PDD-NOS. Use of standardized assessments like ADOS-G, and ADI-R need to be encouraged. This will help in standardizing the assessment procedures used to diagnose children with autism.

We expected that the rural population will face more challenges as compared to the urban population. However, due to uneven number of parents from the rural and urban areas, results of this study cannot be generalized to rural population. Therefore, a true rural population who are not connected to a network of services needs to be considered in future research.

Also, there is a possibility that parents may have declined services that were offered to them only to follow the non-conventional alternative therapies based on anecdotal evidence of effectiveness. Future studies should focus on whether this is prevalent and the possible factors relating to this issue.

Another area that needs to be studied is the severity of symptoms of autism. It may be helpful to know if the severity of symptoms leads parents to be more satisfied and less stressful. It may also be argued that lesser the severity of symptoms, harder it might be to get services, and thus more stressful.

We studied type of diagnosis as a possible correlate of current stress, however, we did not explore whether the parent stress at diagnosis differs with the diagnosis of the child. This may need to be explored in future studies.

Summary

It is evident that the diagnosis of autism is becoming more systematic and is being received at much younger ages than before. Although we have not pinpointed the cause of autism yet, there are some promising results which may soon lead to a groundbreaking discovery. Till that time, it is the duty of the researchers, and professionals to convey accurate information to the public regarding available empirically supported treatments. With the increased information outflow and more access to services, parents are facing the challenge of choosing the right treatment for their child. The current study meets that goal.

Results of our study suggested no link between current stress and satisfaction of services in our sample. However, it was found that parents continue to experience clinical levels of stress as they seek services. This stress was not significantly related to the child's age of the diagnosis. This might suggest that all parents regardless of the age of diagnosis experience clinical levels of stress. Furthermore, it was found that there was no correlation between the level of difficulty in obtaining a diagnosis and parent stress at diagnosis. Parents living in rural areas did not differ significantly from those living in

urban areas based on their satisfaction and stress scores. Finally, the diagnostic groups did not differ significantly based on the current parent stress scores and satisfaction with services. Exploratory analysis showed that the diagnostic groups differed based on their age of diagnosis. This raises issues about the diagnosis of any of the Pervasive Developmental Disorders, which need to be addressed further. Furthermore, the results regarding the time professionals spent need to be confirmed. Either the professionals' insensitivity to parent reactions may have caused more stress, or professionals may have been unable to discuss parents' reactions because parents may have been highly stressed. Although some of the analyses did not yield significant correlates of stress, it was clear that parents were experiencing high levels of stress. Since autism is a spectrum disorder, it may be hard to pinpoint the stress stemming from the unique challenges faced by these parents.

It is thus clear that the field of autism is constantly evolving and needs further research. The diversity of symptoms of children within the autism spectrum may complicate research with this population. It is challenging to formulate research strategies which will take these issues into consideration. Thus collaboration between professionals may be helpful in developing new ideas to conduct further research.

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TABLE 1.

AGE OF FIRST CONCERN, REFERRAL, DIAGNOSIS, AND INTERVENTION

Age	First concerned (N = 112)%	Referral (N = 125)%	Diagnosis (N = 124) %	Intervention (N= 122)%
Upto 1 year	35.0	4.0	0.8	4.9
1 + to 2 years	49.1	45.6	25.8	29.5
2 + to 3 years	13.4	36.0	42.7	37.7
3 + to 5 years	2.7	10.4	21.7	22.1
5 + to 8 years	0.0	4.0	8.8	5.7

Note. The total number of participants (N) is varying for each of the above mentioned variables because data were missing for the rest of the participants.

TABLE 2.
 DIAGNOSTIC EVALUATIONS CONDUCTED FOR THE FIRST TIME AFTER
 BEING CONCERNED AND DURING THE SECOND OPINION DIAGNOSIS.

Tests	1st Diagnosis (<i>N</i> = 126) %
Autism Diagnostic Observation Schedule (ADOS)	26.2
Mullen's Scales of Early Development	16.7
Autism Diagnostic Interview-Revised (ADI-R)	13.5
Gilliam Autism Rating Scale (GARS)	19.8
Childhood Autism Rating Scale (CARS)	27.8
Asperger Syndrome Diagnostic Scale (ASDS)	7.1
Adaptive Behavior Scale	13.5
Checklist for Autism in Toddlers (CHAT)	18.3
Don't know	31.7
Any other	29.4

Note. Parents endorsed more than one test that was conducted during the evaluation.

TABLE 3.

PARENTS' REACTIONS AND THOUGHTS AFTER THEIR CHILD'S DIAGNOSIS.

Reactions	(<i>N</i> = 125) %
I was confused	12.0
I was mad	13.6
I was depressed	35.2
I was completely stressed out	20.8
I felt "Why us?"	32.0
I did not know what to do next	26.4
I felt relieved to get a diagnosis	64.8
Other	40.0

Thoughts	(<i>N</i> = 124) %
How can I help find my child the best treatment available?	90.3
What services should my child receive now?	7.1
Will my child be able to lead a normal life?	82.3
How will I financially support services necessary for my child?	53.2
Will my child be like this forever?	50.8
What will my family think?	14.5
What will my friends think?	10.5

TABLE 4.

COPING STRATEGIES OF PARENTS WHEN THEIR CHILD WAS DIAGNOSED.

Coping Strategies	(<i>N</i> = 126) %
I talked to family	93.3
I talked to friends	63.3
I joined a support group	66.7
I started looking for services immediately after the diagnosis	70.0
I attended autism conferences	30.0
I sought spiritual support	40.0

Note. Parents could check more than one option on this question.

TABLE 5.

TIME SPENT BY PROFESSIONAL DURING THE INTERPRETIVE CONFERENCE.

Time spent	Discussion about Diagnosis (<i>N</i> = 121) %	Discussion about Reactions (<i>N</i> = 92) %	Discussion about Seeking interventions (<i>N</i> = 97) %
Less than half session	28.9	57.6	46.4
Half a session	24.8	19.6	39.2
More than half session	12.4	6.5	5.2
1 full session	33.9	16.3	9.3

Note. 1 full session is approximately 1 hour.

TABLE 6.
INTERVENTION SERVICES RECEIVED FOR THE FIRST TIME AFTER
DIAGNOSIS

Type of Services	Speech (<i>N</i> = 126) %	^a OT (<i>N</i> = 124) %	Special Education (<i>N</i> = 120) %
Clinic Based	23.8	28.2	4.2
School Based	58.7	58.9	65.8
University-based	4.0	0.0	0.0
Home intervention	18.3	15.3	13.3
State Funded	19.8	16.9	10.0
Other	8.7	7.3	9.2
Mean number of hours	1.85	1.45	-
/week (S.D.)	(<i>N</i> = 116)	(<i>N</i> = 105)	(<i>N</i> = 89)

^a OT. Occupational Therapy.

Note. Since children received a variety of services simultaneously, parents could check more than one option on this question.

TABLE 7.
CURRENT INTERVENTION SERVICES

Type of Services	Speech (N = 119) %	OT (N = 116) %	Special Education (N = 110) %
Clinic Based	20.2	22.4	1.8
School Based	74.8	67.2	73.6
University-based	2.5	0.0	0.0
Home intervention	9.2	8.6	10.9
State Funded	7.6	7.8	8.2
Other	8.4	8.6	10.0
Mean number of hours per week (S.D.)	1.80 (1.35) (N = 100)	1.47(1.53) (N = 95)	** (N = 84)

* *Occupational Therapy*

** *45.2% of the children received less than 10 hours, 17.8% received 10-20 hours, and 36.9% received more than 20 hours of special education services.*

TABLE 8.
 AVERAGE NUMBER OF MILES PARENTS HAVE/HAD TO TRAVEL EVERY
 WEEK FOR SERVICES.

Miles	Immediate Post-Diagnosis Intervention (N = 119) %	Current Intervention (N = 107) %
None	24.3	27.1
Up to 10 miles	31.0	33.6
11-20 miles	15.1	18.6
21-40 miles	10.0	10.2
41-70 miles	8.4	6.5
Above 70 miles	10.9	3.7

TABLE 9.
GEOGRAPHICAL LOCATION OF CURRENT RESIDENCE, DIAGNOSIS
RECEIVED, AND INTERVENTION SERVICES.

Time	Urbanized Area	Urbanized Cluster and Rural Areas
	Population > 50,000	Population < 50,000
	%	%
Diagnosis (N = 125)	72.8	27.2
First Intervention (N = 124)	54.0	46.0
Current Intervention (N = 110)	51.7	48.3
Current Residence (N = 117)	46.2	53.8

TABLE 10.

LEVELS OF PARENT STRESS EXPERIENCED DURING DIAGNOSIS

Level of stress	(N = 126) %
Not at all stressed	4.8
Little stressed	7.1
Mildly stressed	3.2
Moderately stressed	20.6
Highly stressed	11.9
Significantly stressed	12.7
Extremely stressed	39.7

TABLE 11.

TOTAL STRESS SCORES ON PARENT STRESS SCALE (PASS) AND PERCEIVED
STRESS SCALE (PSS-10)

Measures	Mean Total Scores
Parent Stress Scale (Possible Range = 18-90)	42.4 (<i>S.D.</i> = 9.6, <i>Range</i> = 25-78)
Perceived Stress Scale -10 (Possible Range = 0-40)	19.72 (<i>S.D.</i> = 6.4, <i>Range</i> = 3 -35)

TABLE 12.

SATISFACTION WITH CURRENT SERVICES

Responses	Speech %		OT* %		Beh. Therapy %	
	School	Private	school	private	school	home
	N = 108	N = 61	N = 105	N = 53	N = 105	N = 65
Not at all satisfied	5.6	4.9	11.4	3.8	3.8	7.7
Minimally satisfied	7.4	1.6	10.5	1.9	3.8	3.1
Mildly satisfied	9.3	1.6	9.5	3.8	6.7	6.2
Neutral	17.6	11.5	26.7	13.2	14.3	23.1
Moderately satisfied	19.4	16.4	13.3	13.2	17.1	15.4
Highly satisfied	19.4	31.1	10.5	13.2	35.2	29.2
Fully satisfied	21.3	32.8	18.1	50.9	19.0	15.4

* Occupational Therapy

TABLE 13.

PARENT PREFERENCES ABOUT THERAPY

Statements	Disagree %	Agree %
I would prefer to have a therapist work directly one on one with my child rather than training me to be my child's therapist. (N =126)	34.1	52.4
I think my child should have been involved in 40 hours a week of therapy. (N =126)	45.2	40.5
I would rather have the therapist teach me strategies to work with my child rather than working directly with my child. (N =126)	46.8	27.8
I would like the therapist to work with my child one on one and simultaneously train me to work with him. (N = 125)	5.6	84.8
I would like the therapist to train me to train other people in the community (university students) who can work with my child. (N =124).	29.8	49.2

Note. The remaining percents for each of the statements represent that parents had neutral feelings about the statements.

TABLE 14.

CORRELATIONS BETWEEN PASS, PSS, AND PARENT SATISFACTION

	PASS	PSS	Speech School	Speech Private	OT School	OT Private	Sp. Ed. School	aB.T. Home	Other
PASS	1	0.55**	-0.15	-0.13	-0.02	0.04	-0.05	0.09	-0.27*
PSS		1	0.01	-0.04	-0.00	0.01	-0.10	-0.12	-0.24
Speech School			1	0.44**	0.51**	0.31*	0.64**	0.30*	0.26
Speech Private				1	0.33*	0.58**	0.29*	0.23	0.02
OT School					1	0.47**	0.50**	0.13	0.10
OT Private						1	0.27	0.11	0.22
Special Ed. School							1	0.33**	0.25
Behavior therapy Home								1	0.25
Other									1

aB.T. Behavior Therapy

** Correlation is significant at 0.01 level (2-tailed).

* Correlation is significant at 0.05 level (2-tailed).

APPENDIX A
Informed Consent

INFORMED CONSENT

Title of the Study: A Survey of Parent Stress and Satisfaction about Services for Children with Pervasive Developmental Disorders.

Investigators: Shital Gaitonde, M.Ed., Maureen Sullivan, Ph.D.

Purpose: I understand that this survey will be helpful in understanding what it is like for a parent when their child is diagnosed with Pervasive Developmental Disorders (PDD) or Autism. It will also help to gather information on parent satisfaction with services received.

Procedures: I understand that I will be asked to complete a survey about obtaining a diagnosis and treatment services for my child. The survey will include questions about my child's assessment and treatment services. I will be asked about my emotional reaction to the diagnosis and treatment received. In addition, I will also be asked about my ethnicity, number of people working in the family, total family members, annual family income and parents' education level.

Risks of participation:

I understand that there are no known risks associated with this study. However, some parts of the study may be uncomfortable to complete. If I feel uncomfortable and wish to withdraw, I would be allowed to do so at any time during the participation. I may also choose to skip questions that make me feel uncomfortable.

Benefits:

This survey will be helpful in the development of better services for children with pervasive developmental disorders or autism. There are no direct benefits to my family. However, this survey may help me consolidate my ideas and give me an opportunity to reflect on my experiences. My experiences will be used in improving services for children with autism. Results from the study will be shared with other professionals and thus will benefit the community.

Confidentiality:

I understand that the information collected from me during this study will be confidential. The consent form and the sheet containing my name, contact information and the code number will be stored separately in a locked cabinet in the lab that is only used by researchers and research assistants. The identifying information from the online survey will be stored in a separate secure database in the lab. The information will be kept for 5 years after the results are published.

The results of this study may be presented at meetings or in publications; however, my family's identity will not be disclosed in those presentations. This information will be used for research purposes only. If I wish to have the results of this survey for personal use, I can obtain those from the investigators.

Representatives from the OSU Institutional Review Board for the Protection of Human Subjects and its federal oversight agencies may need to look at the consent and data records to make sure that they are being handled in agreement with approved procedures. These representatives will maintain the confidentiality of this information.

Contacts:

I may contact the following persons if I wish to obtain further information regarding this study:

1. Shital Gaitonde
Psychology Department,
Oklahoma State University
215 North Murray Hall,
Stillwater, OK 74078
Email: shital.gaitonde@okstate.edu

2. Dr. Maureen Sullivan
Psychology Department,
Oklahoma State University
215 North Murray Hall,
Stillwater, OK 74078
Phone: 405-744-6027
Email: Maureen.sullivan@okstate.edu

3. If I have questions about the research and my rights as a research volunteer, I may contact Dr. Sue C. Jacobs, IRB Chair, 219 Cordell North, Stillwater, OK 74078, 405-744-1676 or irb@okstate.edu.

Participant Rights:

I understand that my participation is voluntary. There is no penalty for refusal to participate, and I am free to withdraw my consent and participation in this study at any time without any penalty.

Signatures:

I have read and fully understand the consent form. I sign it freely and voluntarily. A copy of this form has been given to me.

Signature of Participant

Date

APPENDIX B

Personal Information

PERSONAL INFORMATION

<p>Code Number (First three letters of child's last name, month and year of birth e.g. John Smith born in Nov 2000 will have the code SMI112000)</p>
<p>Name of the child</p>
<p>Mailing Address</p>
<p>Telephone number</p>

Date: _____

Code # _____

APPENDIX C.

Early Autism Experiences Survey

EARLY AUTISM EXPERIENCES SURVEY**Instructions**

This survey takes approximately 30- 40 minutes to complete. Please answer the following questions as best as you can. Some questions are multiple choice questions. Mark as many choices as are applicable to your situation. Any additional information that you can provide in the comments section will be appreciated. Please make sure you answer every question. If you feel you cannot answer a question or need any clarification, provide an answer that you think might best answer it. Your opinions whether positive or negative are crucial to this study and will be respected.

1. How old is your child now?
2. Describe your relationship with the child.
<input type="checkbox"/> Biological mother <input type="checkbox"/> Biological father <input type="checkbox"/> Stepmother <input type="checkbox"/> Stepfather <input type="checkbox"/> Foster parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Sibling <input type="checkbox"/> Any other:
3. What is your child's most current diagnosis?
<input type="checkbox"/> Autistic disorder <input type="checkbox"/> Rett's disorder <input type="checkbox"/> Asperger's Disorder <input type="checkbox"/> Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) <input type="checkbox"/> Childhood Disintegrative Disorder (CDD) <input type="checkbox"/> Don't know. <input type="checkbox"/> Other. Explain:

SECTION 2 : FIRST CONCERNS

4. **How old was your child when you were first concerned?**

5. **Who first noticed concerns?**

- Me
- My spouse
- Sibling
- Family
- Friend.
- Family doctor/ Primary care physician
- Pediatrician
- Teacher
- School psychologist
- Other school personnel. If yes, explain:
- Case worker/Health Department Case manager/Developmental disabilities specialist
- Day care personnel
- Any other:

6. **What were the first concerns?**

- My child would not look at others while talking.
- My child would play on his/her own.
- My child would play with the same toy for hours.
- My child was slow to start talking.
- My child would not talk as much as the other children his age.
- My child would talk in a language much higher for his age.
- My child would repeat after others.
- My child would have difficulty changing from one activity to another.
- My child was not meeting the state's developmental markers.
- Other:

7. When you noticed these concerns, what was/were your initial reaction/s as a parent? (Mark all that are applicable)

- I thought that he would outgrow the problem.
- I was in denial.
- I decided not to think about it.
- I expressed concerns to my family.
- I expressed concerns to my friends.
- I immediately contacted the pediatrician.(within a week after the concerns were noticed)
- I immediately searched the web to find out more about the condition.(within a week after the concerns were noticed)
- I joined an online support group for parents with similar concerns.
- I was so worried that I had to seek professional help for myself.
- Specify any other reactions:

SECTION 3 : REFERRALS AND INITIAL DIAGNOSIS

8. How old was your child when he/she was referred for evaluation?

9. Who referred the child for a diagnostic assessment? (Mark all that are applicable)

- Family doctor/Primary Care Physician (PCP)
- Pediatrician
- Teacher
- School psychologist
- Other School Personnel. If yes, explain:
- Case worker/Health Department Case manager/Developmental disabilities specialist
- Specialty clinic
- Any other:

10. How old was your child when he/she was diagnosed?

11. What were the diagnostic tests conducted?(As mentioned in the report if available) (Mark all that are applicable)

- Autism Diagnostic Observation Schedule (ADOS)
 Mullen's scales of Early Development
 Autism Diagnostic Interview- Revised (ADI-R)
 Gilliam Autism Rating Scale (GARS)
 Childhood Autism Rating Scale (CARS)
 Asperger Syndrome Diagnostic Scale
 Adaptive behavior scale
 Checklist for Autism in Toddlers (CHAT)
 Don't know
 Any other. Explain:

12. Who diagnosed the child for the first time?

- Family doctor/Primary Care Physician (PCP)
 Pediatrician
 Psychiatrist
 Clinical child psychologist
 School psychologist
 Case worker/Health Department Case manager/Developmental disabilities specialist
 Specialty clinic/ A team of professionals including occupational therapist/physiotherapist.
 Any other:

13. What was the initial diagnosis received (as mentioned in the assessment report)?

- Autistic disorder
 Rett's disorder
 Asperger's Disorder
 Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
 Childhood Disintegrative Disorder (CDD)
 Don't know.
 Other. Explain:

Is the above diagnosis the most current diagnosis?

- Yes No

SECTION 4: SECOND OPINION DIAGNOSIS

14. Did you seek a second opinion for the diagnosis? Yes No.

Note: Answer questions 15-17 ONLY if you answered yes to question 16.

15. If you sought a second opinion, then what was the next diagnosis received?

16. What diagnostic evaluations were conducted this second time to make that diagnosis? (Mark all that are applicable)

- Autism Diagnostic Observation Schedule (ADOS)
- Mullen's scales of Early Development
- Autism Diagnostic Interview- Revised (ADI-R)
- Gilliam Autism Rating Scale
- Childhood Autism Rating Scale
- Asperger Syndrome Diagnostic Scale
- Adaptive behavior scale
- Any other. Explain:
- Don't know

17. What age was this diagnosis received/ or previous diagnosis confirmed?

SECTION 5: MOST RECENT DIAGNOSIS

Please answer questions 18-30 regarding the most current diagnosis for your child.

18. What age was the most recent diagnosis received?

19. Who made this most recent diagnosis?

- Family doctor/Primary Care Physician (PCP)
 Pediatrician
 Psychiatrist
 Clinical child psychologist
 School psychologist
 Case worker/Health Department Case manager/Developmental disabilities specialist
 Specialty clinic/A team of professionals including Occupational therapist, physiotherapist.
-
- Any other:

20. How did you react to this diagnosis? (Mark all that are applicable)

- I was confused
 I was mad
 I was depressed
 I thought the doctor did not know what he was talking about.
 I thought that the doctor did not know the child well enough to make the correct diagnosis.
 I sought a second opinion.
 I sought help from another doctor with the hope that Autism was the wrong diagnosis for my child.
 I did not know what to do next.
 I was completely Stressed out
 I felt "Why us?"
 I felt relieved to get the diagnosis.
 Other:

21. What did you think caused autism?

- My behavior
 My genes
 Birth complications (emergency c-section, chord around the neck, forceps delivery, did not cry at birth, had to be kept in the NICU at birth)
 His/her brain structure
 Chemical imbalance within the child
 May be it runs in the family
 Vaccinations
 Any Other:

22. Describe child's strengths noted during diagnostic testing? (e.g. affectionate, easy tempered, focused)

23. Which city and state was the diagnosis received in?

24. What size was the town (in terms of population) in which the diagnosis was received?

- less than 500
- 500-999
- 1000-1499
- 1500-1999
- 2000-4999
- 5000-9999
- 10000-19999
- 20000-49999
- 50000-99999
- 100000 and above

25. What were your initial thoughts after receiving diagnosis?

- Will my child be like this forever?
- Will he be able to lead a normal life?
- What will my friends think?
- What will my family think?
- How will I financially support services necessary for his treatment?
- What services should my child receive now?
- How can I help my child find the right treatment?
- Any other:

26. Indicate the level of agreement with the following statement. You may mark the level that best reflects your preferences or thoughts.

I wish my child would have been diagnosed at an earlier age.

**Strongly
Disagree**

1

2

3

4

5

6

7

Neutral

**Strongly
agree**

27. Mark the level of stress you experienced when your child was diagnosed.

**Not at all
stressed**

1

2

3

4

5

6

7

**Moderately
stressed**

**Extremely
Stressed**

28. What were some ways in which you sought emotional support for you and your family after receiving a diagnosis?

- I talked to family
- I talked to friends
- I sought spiritual support
- I sought psychological counseling.
- I joined autism support groups
- I took a vacation
- I isolated myself from my friends and family. I just did not want to be bothered.
- I attended autism conferences
- I started looking for services (within a week of receiving the diagnosis)
- Any other:

29. How much money was spent approximately on testing and diagnosis for your child?

30. Using the scale below, mark the level of difficulty you experienced in finding resources to get a diagnostic assessment.

**Not
at
all**

**Moderately
difficult**

**Extremely
Difficult**

1

2

3

4

5

6

7

SECTION 6: POST DIAGNOSIS

31. How did you know what to do next?

- I followed my doctor's advice.
- I contacted the agencies that the clinician had made referrals to.
- I searched for information and contacted agencies on my own.
- I talked to friends and asked if they knew anything about the disorder or services related to it.
- I collected information from the internet.
- I read books and tried following the recommendations from those books.
- I joined a local network of families with similar diagnosis.
- I thought he/she will outgrow the problem and so I did not try to seek any help at that time.
- Any other:

32. How long after the diagnosis did you seek help?

- Within a week
- 1 week – 1 month
- 1-3 months
- 3-6 months
- 6 months- 1 year
- 1-2 years
- Other. Explain:

33. What was the next step after getting the above information?

- Visited a Specialist
- Talked to school about getting services
- Were told not to worry and he will outgrow, so we were not worried about services at this point.
- Started services immediately. If yes specify services (speech, OT, home intervention, Psychology):
- Sought professional help specifically for this disorder (e.g. ABA therapist, Clinical child psychologist specializing in Autism.)
- Other:

34. After receiving the diagnosis, did the professional making the diagnosis, spend time with you to discuss the disorder?

- Yes No

35. How long did the professional spend on the initial discussions about the disorder? (1 session is approximately equal to 1 hour)

- Half a session More than half a session Less than half session One full session

36. After receiving the diagnosis, did the professional making the diagnosis, spend time with you to discuss your reactions?

- Yes No

37. How long did the professional spend on the initial discussions about your reactions? (one session is approximately equal to 1 hour)

- Half a session More than half a session Less than half session One full session

38. After receiving the diagnosis, did the professional making the diagnosis, spend time with you to discuss the possibilities of seeking interventions?

Yes No

39. If yes, then how long did the professional spend on the initial discussions about the possibilities of seeking interventions? (one session is approximately equal to 1 hour)

Half a session More than half a session Less than half session One full session

40. Indicate the level of agreement with the following statement. Mark the level that best reflects your preferences or thoughts.

It would have been helpful if the professional making the diagnosis would have spent time discussing the prognosis and the future recommendations for my child.

Strongly disagree

1

2

3

4

5

6

7

Strongly agree

SECTION 7 : FIRST INTERVENTION SERVICES

Questions 41-51: *Provide information regarding the services received for the first time after diagnosis.*

41. How old was your child when specific services related to the diagnosis were received for the first time?

42. Indicate the level of agreement with the following statement. Mark the level that best reflects your preferences or thoughts.

I wish my child would have started receiving intervention at an earlier age.

Strongly disagree

1

2

3

4

5

6

Strongly agree

7

Neutral

43. What type of services were/are being received?

- Clinic based
- School based
- University based training clinic
- Home intervention
- State funded services e.g. Sooner Start, Early Headstart
- Other. Specify:

44. Type of programs that are/were done:

- ABA
- TEACCH
- Lovaas
- Denver Model
- Other (Specify):

45. How many hours per week are being/ were services received in each type of therapy with each of the professionals?			
Profession (speech/OT/SpeEd)	Type of therapy (clinic based, home intervention, school)	# of hours per week	
a. Speech	<input type="checkbox"/> Clinic based <input type="checkbox"/> School based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early Headstart <input type="checkbox"/> Other. Specify:		
b. OT	<input type="checkbox"/> Clinic based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early Headstart <input type="checkbox"/> Other. Specify:		
c. Special education	<input type="checkbox"/> Clinic based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early Headstart <input type="checkbox"/> Other. Specify:		
46. How much money was/is being spent per year approximately on early intervention for your child?			

47. In which city and state are /were intervention services received?			

<p>48. What was the size of the town (in terms of population) in which intervention services were received?</p> <hr/> <input type="checkbox"/> less than 500 <input type="checkbox"/> 500-999 <input type="checkbox"/> 1000-1499 <input type="checkbox"/> 1500-1999 <input type="checkbox"/> 2000-4999 <input type="checkbox"/> 5000-9999 <input type="checkbox"/> 10000-19999 <input type="checkbox"/> 20000-49999 <input type="checkbox"/> 50000-99999 <input type="checkbox"/> 100000 and above																					
<p>49. How many miles on an average have/had to drive to get services?</p> <hr/>																					
<p>50. How many hours on an average are/were spent by family on treatment per week?</p> <hr/>																					
<p>51. Using the scale below, circle the overall level of satisfaction of the current intervention services that are/were received?</p> <hr/> <table style="width: 100%; border: none;"> <tr> <td style="text-align: center; vertical-align: top;"> <p>Not at all satisfied</p> </td> <td></td> <td></td> <td style="text-align: center; vertical-align: top;"> <p>Neutra l</p> </td> <td></td> <td></td> <td style="text-align: center; vertical-align: top;"> <p>Fully satisfied</p> </td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> </tr> </table>	<p>Not at all satisfied</p>			<p>Neutra l</p>			<p>Fully satisfied</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1	2	3	4	5	6	7
<p>Not at all satisfied</p>			<p>Neutra l</p>			<p>Fully satisfied</p>															
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>															
1	2	3	4	5	6	7															

<p>SECTION 8: CURRENT SERVICES</p>
<p>52. Does your child still receive any intervention services? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <hr/> <p><i>For questions 53-64: If services have changed from the previous services received as reported in questions 41-51, then provide information here regarding the CURRENT services which are being received. If the previous services have not changed or no services are being received currently, then skip section 8.</i></p>

53. What types of services are being received?

Clinic based
 School based
 University based training clinic
 Home intervention
 State funded services e.g. Sooner Start, Early Headstart
 Other:

54. Type of programs that are done:

ABA
 TEACCH
 Denver Model
 Other (Specify):

55. How many hours per week are being services received in each type of therapy with each of the professionals?

Profession (speech/OT/SpEd)	Type of therapy (clinic based, home intervention, school)	# of hours per week	
Speech	<input type="checkbox"/> Clinic based <input type="checkbox"/> School based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early Headstart <input type="checkbox"/> Other. Specify:		
OT	<input type="checkbox"/> Clinic based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early Headstart <input type="checkbox"/> Other. Specify:		
Special education	<input type="checkbox"/> Clinic based <input type="checkbox"/> University based training clinic <input type="checkbox"/> Home intervention <input type="checkbox"/> State funded services e.g. Sooner Start, Early		

	Headstart <input type="checkbox"/> Other. Specify:		
56. How much money is being spent per year approximately on early intervention for your child? <hr/>			
57. In which city and state are most current services being received? <hr/>			
58. What size is the town (in terms of population) in which most current intervention services are being received? <input type="checkbox"/> less than 500 <hr/> <input type="checkbox"/> 500-999 <input type="checkbox"/> 1000-1499 <input type="checkbox"/> 1500-1999 <input type="checkbox"/> 2000-4999 <input type="checkbox"/> 5000-9999 <input type="checkbox"/> 10000-19999 <input type="checkbox"/> 20000-49999 <input type="checkbox"/> 50000-99999 <input type="checkbox"/> 100000 and above			
59. How many miles on an average have to drive to get services? <hr/>			
60. How many hours do you and your family spend on an average every week on intervention? <hr/> <input type="checkbox"/> None <input type="checkbox"/> less than 5 hours <input type="checkbox"/> 5-10 hours <input type="checkbox"/> 10-20 hours <input type="checkbox"/> 20-40 hours <input type="checkbox"/> More than 40 hours			

61. Using the scale below, mark the level of difficulty you experienced in finding resources to get a diagnostic assessment.

Not at all				Moderately difficult			Extremely Difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3		4	5	6	7

SECTION 9 :SATISFACTION WITH SERVICES

For section 9, provide information about the most current services that are being received. Using the scale below, circle the level of satisfaction of the current intervention services being received? Check only those that are applicable)

62. Speech therapy (school):

Not at all satisfied				Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3		4	5	6	7

63. Speech therapy (private):

Not at all satisfied				Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3		4	5	6	7

64. Occupational therapy (school):						
Not at all satisfied			Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
65. Occupational therapy (private):						
Not at all satisfied			Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
66. Special Education (school)						
Not at all satisfied			Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
67. Behavior Therapy (home)						
Not at all satisfied			Neutral			Fully satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7

68. Other services. Explain:**Not at all
satisfied****Neutral****Fully
satisfied****1****2****3****4****5****6****7****SECTION 10 : PREFERENCES****69. Which therapy model would you prefer the most?**

- Therapist-child direct intervention. i.e. The therapist working with the child on a one to one basis.
- Therapist – parent consultative. i.e. The therapist works as consultants to parents who are their child’s own therapists. The therapist trains the parents to implement programs.
- Both of the above
- Therapist training the parent to train their own therapists.
- Other:

For questions 70-74, indicate the level of agreement with each of the statements. You may encircle the level that best reflects your preferences or thoughts.

70. I would prefer to have the therapist work directly one on one with my child rather than training me to be my child’s therapist.**Strongly
Disagree****Neutral****Strongly
agree****1****2****3****4****5****6****7**

71. I think my child should be involved in 40 hours a week of therapy.						
Strongly Disagree			Neutral			Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
72. I would rather have the therapist teach me strategies to work with my child rather than working directly with my child.						
Strongly Disagree			Neutral			Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
73. I would like the therapist to work with my child one on one and simultaneously train me to work with him.						
Strongly Disagree			Neutral			Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7
74. I would like the therapist to train me to train other people in the community (university students) who can work with my child.						
Strongly Disagree			Neutral			Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7

SECTION 11: CURRENT STATUS OF THE CHILD

75. Current strengths of your child

76. Current needs of your child

77. Indicate the level of agreement with each of the statements. You may check the level that best reflects your preferences or thoughts.

I am satisfied and happy with the way therapy is working for my child.

Strongly Disagree

1

2

3

Neutral

4

5

6

Strongly agree

7

78. Using the scale below, mark the level of progress your child has made since you were first concerned.

No progress				Moderate Progress			Excellent progress
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7	

79. Describe the progress that your child has made since the diagnosis.

80. Any other comments:

APPENDIX D

Parent Stress Scale

Parental Stress Scale

(Berry, J. O., & Jones, W. H. (1995).

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

- ___ 1. I am happy in my role as a parent.
- ___ 2. There is little or nothing I wouldn't do for my child(ren) if it was necessary.
- ___ 3. Caring for my child(ren) sometimes takes more time and energy than I have to give.
- ___ 4. I sometimes worry whether I am doing enough for my child(ren).
- ___ 5. I feel close to my child(ren).
- ___ 6. I enjoy spending time with my child(ren).
- ___ 7. My child(ren) is an important source of affection for me.
- ___ 8. Having child(ren) gives me a more certain and optimistic view for the future.
- ___ 9. The major source of stress in my life is my child(ren).
- ___ 10. Having child(ren) leaves little time and flexibility in my life.
- ___ 11. Having child(ren) has been a financial burden.
- ___ 12. It is difficult to balance different responsibilities because of my child(ren).
- ___ 13. The behavior of my child(ren) is often embarrassing or stressful to me.
- ___ 14. If I had it to do over again, I might decide not to have child(ren).
- ___ 15. I feel overwhelmed by the responsibility of being a parent.
- ___ 16. Having child(ren) has meant having too few choices and too little control over my life.
- ___ 17. I am satisfied as a parent.
- ___ 18. I find my child(ren) enjoyable.

APPENDIX E

Perceived Stress Scale

Perceived Stress Scale- 10 Item

Cohen, S., Kamarck, T., Mermelstein, R. (1983).

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way

In the last month, how often have you been upset because of something that happened unexpectedly?

never almost never sometimes fairly often very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?

never almost never sometimes fairly often very often

3. In the last month, how often have you felt nervous and "stressed"?

never almost never sometimes fairly often very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

never almost never sometimes fairly often very often

5. In the last month, how often have you felt that things were going your way?

never almost never sometimes fairly often very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

never almost never sometimes fairly often very often

7. In the last month, how often have you been able to control irritations in your life?

never almost never sometimes fairly often very often

8. In the last month, how often have you felt that you were on top of things?

never almost never sometimes fairly often very often

9. In the last month, how often have you been angered because of things that were outside of your control?

never almost never sometimes fairly often very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

never almost never sometimes fairly often very often

APPENDIX F

Demographic Information

Demographic information

1. Sex

Male Female

2. Age (in years)

3. Race

Caucasian African America Hispanic Native American Asian
American Other

4. Marital Status

never married married living together divorced or separated
 widowed

5. What size (in terms of population) of town do you live in ?

Less than 500 500-999 1000-1499 1500-1999 2000-4999 5000-9999
 10,000-19999 20,000-49,000 50,000-99,000 100,000 or greater

6. Indicate how long you went to graduate school

- Graduate or professional training
- Partial graduate or professional training
- College graduate (degree obtained)
- partial college training (which may include technical school beyond high school.
- High school graduate (or graduate of a technical school or trade school)
- partial high school (10th grade through partial 12th grade)
- partial junior high school (7th grade through 9th grade)
- Elementary school (6th grade or less)

7. Number of people in the family who are working :

8. Total number of people dependent on the household income other than the people working:

9. Annual Household income:

10. Are you a member of any parent organization/parent group/local parent network ?

If yes, name the organization/s

APPENDIX G

IRB Approval

Oklahoma State University Institutional Review Board

Date: Wednesday, April 18, 2007
IRB Application No AS0724
Proposal Title: A Survey of Parent Stress and Satisfaction About Services for Children With Pervasive Development Disorders
Reviewed and Processed as: Expedited

Status Recommended by Reviewer(s): Approved Protocol Expires: 4/17/2008

Principal Investigator(s)

Shital Gaitonde
14365 S. Urbana Pl.
Bixby, OK 74008

Douglas Scambler
215 N Murray
Stillwater, OK 74078

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

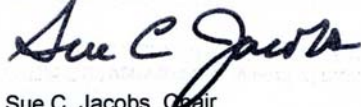
The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact Beth McTernan in 219 Cordell North (phone: 405-744-5700, beth.mcternan@okstate.edu).

Sincerely,



Sue C. Jacobs, Chair
Institutional Review Board

VITA

Shital Pramod Gaitonde

Candidate for the Degree of

Master of Science

Thesis: A SURVEY OF PARENT SATISFACTION ABOUT SERVICES FOR CHILDREN WITH PERVASIVE DEVELOPMENTAL DISORDER

Major Field: Psychology

Biographical:

Personal Data: Born in Mumbai, India, On November, 7, 1977, the daughter of Pramod and Indubala Gaitonde.

Education: Received a Bachelor of Science degree in Occupational Therapy and a Bachelor of Education degree in Special Education from Mumbai University, India in May 1999 and June 2001 respectively; received a Master of Education degree in Special Education from University of Texas at Austin in December 2002; Completed the requirements for the Master of Science in Psychology at Oklahoma State University, Stillwater, Oklahoma in May 2008.

Experience: Employed as a behavior analyst at Devereux Foundation; employed as an home intervention therapist at University of Colorado Health Sciences Center, Denver, Colorado; employed by Oklahoma State University, Department of Psychology as a graduate assistant 2005-present.

Professional Memberships: Member of American Psychological Association

Name: Shital Gaitonde

Date of Degree: May, 2008

Institution: Oklahoma State University

Location: Stillwater, Oklahoma

Title of Study: A SURVEY OF PARENT SATISFACTION ABOUT SERVICES FOR
CHILDREN WITH PERVASIVE DEVELOPMENTAL DISORDER.

Pages in Study: ###

Candidate for the Degree of Master of Science

Major Field: Psychology

Scope and Method of Study: The current study updated the results from the Howlin and Moore (1997) study and furthermore evaluated some specific issues regarding the diagnostic and intervention process for parents of children with autism. The possible correlates of parent stress such as satisfaction with services, geographical location, age and type of diagnosis were explored. 126 parents of children with Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified completed the study. They completed demographic information; Early Autism Experiences Survey; and stress measures; such as Parental Stress Scale and the Perceived Stress Scale. Both, parent stress at diagnosis and current stress were measured. Descriptive statistics were reported for the age at which the diagnosis was received, and the age at which intervention services were first received. Pearson's coefficient of correlation and Analysis of Variance (ANOVA) were used to test the seven hypotheses.

Findings and Conclusions: Results showed that the diagnosis of autism is becoming more systematic and is being received at much younger ages than before. The findings in this study suggested no link between current parent stress and satisfaction of services in the sample in our study. However, it was found that parents continue to experience clinical levels of stress as they seek services. This stress was not significantly related to the child's age of the diagnosis. This might suggest that all parents regardless of the age of diagnosis experience clinical levels of stress. Furthermore, it was found that there was no correlation between the level of difficulty in obtaining a diagnosis and parent stress at diagnosis. Parents living in rural areas did not differ significantly from those living in urban areas based on their satisfaction and stress scores. Finally, the diagnostic groups did not differ significantly based on the current parent stress scores and satisfaction with services.

ADVISER'S APPROVAL: Maureen A. Sullivan Ph.D.
