

## **CHAPTER-III**

### **REVIEW OF THE LITERATURE**

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- **Dimitra Tavulari (March 2004), study on** “Communication in children with Autism Spectrum Disorders (ASDs): An inquiry, by means of a case study, into how a pre-school specialist provision for children with ASDs interprets theoretical models of Practice”.

Traditional behavioral approaches in the 1970’s used teaching procedures which were characterized by a one-to-one massed test exercise format to sequence early “readiness” skills in eye contact, attention, and sitting followed by more advanced skills in matching, verbal simulated, receptive and expressive communicating, play and so further. These approaches received much attention, mostly because they were the first to objectively demonstrate that children with autism were able to acquire a number of variety of skills through systematic and scientific teaching methods.

- **Lovaas (1981),** resulted on his study on “**Communication among Autistic Children**” the noted for autistic child for their highly repetitive one-to-one approach was the belief that children with autism were unable to learn in more favorable and natural environments because of their great learning and attention difficulties and the lack of practice opportunities and systematic strengthening in more natural events.
- **According to Reichle and Keogh (1985),** and Sundberg and Partington (1999), both are effective for teaching receptive and expressive language skills to children with ASDs and both are prominent components of a communicative prospectus.

However, it seems that incidental teaching is more appropriate for verbal children with ASDs, although researchers support the view that non-verbal children can also initiate interactions. It seems though that non verbal children will need much more time to reach the point where more explained language is requested from them.

## **THE CASE STUDY**

The present study aimed to identify how experts in a particular pre-school setting for children with ASDs are interpreting and applying strategies, proposed by theorists as methods of good practice in the teaching of communication skills.

The study identified the various strategies recommended while the practical exploration, the actual case study, looks at how experts are interpreting and applying and analyzing these strategies in their everyday contact with the children.

Although much has been written about the enactment and the evaluation of specific intervention strategies for children with ASDs, usually by those proposing a specific approach (e.g. Schopler and Mesibov, 1985; Bondy and Frost, 1994), there has been very little investigation into how practitioners are interpreting and applying this varying and often inconsistent guidance. This current study therefore, by making detailed observation of the implementation of the strategies in a real life setting, informs the debate on how children with ASDs are being taught by evaluating how theorists are impacting upon classroom practice.

The particular pre-school establishment is a specialist provision for children with ASDs and it accommodates children from 2 to 4 years of age.

The findings of the study identified the particular intervention methods used in the nursery, identified the way that practitioners interpret and apply these methods and indicated that they truly positively contribute to the communication development of the children.

### **➤ Sarah Anne Johnson & Jessica Diane Knuth(2007), studied on “A Descriptive Analysis Of Homeschooling Children With Autism”.**

This study concluded the history of homeschooling, including the growth in popularity; relevant legislation and case law; reasons why parents homeschool; types of homeschooling; the benefits and challenges to homeschooling; and an overview of homeschooling children with special needs, including those with autism.

Historical Overview of Current Homeschooling Movement

Although most research on homeschooling has been conducted since 1969 (Plent, 1999), homeschooling is not a new phenomenon. In fact, in the 1700's, parents were homeschooling their children (Plent, 1999). Homeschooling began as a means for families to educate their children while allowing them to participate in home activities, such as farming and cooking, domestic activities that allowed the family to survive.

### **Popular Growth**

Homeschooling continued until the mid-1800s when enforced attendance laws were enacted and states began to regulate the education of children by making it a legal requirement that children attend a public school (Gordon & Gordon, 1990). Between the 1870's and the 1960's, homeschooling was a occurrence seen mostly among rural populations (Gordon & Gordon, 1990; Stevens, 2001). In the 1960's through the 1980's, homeschooling became more widely known with publications by John Holt, including *How Children Fail* (1964) and *Teach Your Own* (1981) (Basham, Merrifield, & Hepburn, 2007). In these books, Holt discussed the notion that public schools do not teach children the values and ideals necessary to be a member of society. These books further suggested that parents "unschool" their children. "Unschooling" is defined as a homeschool structure where there is no fixed learning strategies. The belief is that children learn best through formless, real life experiences in a cultivation home environment, which would create greater independence in educational choice by the parents and a decentralized school community within the United States. Unschooling has been referred to as permissive homeschooling by critics of Holt and his work (Basham, Merrifield, & Hepburn, 2007).

- **Parent and Family Demographic InformationGeographical representation.**
- Within the **state of California, 29 surveys** (69.04% of total) were completed representing a total of 18 out of 58 (31.03% of counties) within the state. Out-of-state respondents (not including California) instituted 13 completed surveys (30.9%), representing 11 out of 50 (22%) states within the country.
- Parental education level of the primary homeschooling parent for California and out-of-state ranged from three (7.14%) being a high school graduate to one having a PhD (2.38%) with 15 (35.71%) parents completing a bachelor's degree and 10 parents (23.81%) completing some college.

- Within California, parental education levels of the primary homeschooling parent ranged from three (10.44%) being a high school graduate to one (3.44%) having a PhD. Of the parents' homeschooling, 12 (41.37%) were college graduates, an additional six (20.68%) of the respondents received a Master's degree with one participant (6.89%) holding a valid California teaching testimonial
- The out-of state parental education levels ranged from six (46.15%) having some college course work completed to three (23.07%) holding a Master's degree. One participant (7.69%) completed an Associates' Degree, while three (3.07%) completed a Bachelor degree. Zero respondents held a teaching credential or Ph.D.
- **Number of children in the family.**
- Data on the number of children within the family was also collected during a follow up survey after the survey closed. Of the 14 participants who responded to the follow-up questions, parents who homeschool a child with autism within California and out-of-state had a range of one to six children.
- Within California, three (33.33%) families had one child, two (22.22%) families had two children, three (33.33%) families had three children and one (11.11%) family had six children. Of the out-of-state participants, two (40%) families had one child, two (40%) families had three children and one (20%) family had four children.
- Four categories emerged in regards to diagnostic information. Out of the total 42 respondents, 12 (28.57%) reported a diagnosis of Asperger syndrome, 25 (59.52%) stated autism, four (7.14%) reported PDD-NOS and one (2.38%) reported spectrum disorder.
- Within the state of California, three (10.34%) described a diagnosis of Asperger syndrome, 23 (78.31%) reported autism as primary diagnosis and the remaining three (10.34%) reported a diagnosis of PDD-NOS. Out-of -state respondents reported 9 (69.23%) with Asperger syndrome, two (15.38%) with autism diagnosis, one (7.69%) with PDD-NOS and one (7.69%) with a spectrum disorder.

**Type of teaching style:**

- After the conclusion of the initial survey, follow-up questions revealed a query about the type of teaching style utilized when homeschooling their child with autism.
- Thirty-eight participants gave their contact information, of this number 14 responded with their teaching style.
- Participants were asked to classify their teaching style into one of five main categories: traditional, unit-study approach, eclectic, unschooling or interest initiate learning, and dual enrollment (homeschool and also go to public school). Of the 14 respondents to this question from both California and out-of-state respondents, 3 (21.42%) used a traditional approach, 1 (7.14%) used a unit-study approach, 1 (7.14%) used an interest initiated approach, 9 (64.29%) reported their approach to be eclectic and zero were dually enrolled.
- Within the state of California, two (22.22%) participants used the traditional approach to homeschool, one (11.11%) used the unit-study approach, five (55.55%) used eclectic, one (11.11%) used interest initiated, and zero were dually enrolled. Of the out-of-state respondents, 1 (20%) reported they used the traditional approach while the remaining four (80%) reported that they used an eclectic approach.

**Parental Rationale For Homeschooling-California Respondents**

- Among California respondents, a theme of overall dissatisfaction with the school district emerged from the parental response regarding main reasons for homeschooling their child with autism.
- These subcategories and the **number and percentage of parents** who noted the areas of **dissatisfaction**:
  - ❖ Concerns with relevance of placement, (11, 37.93%)
  - ❖ A perceived low level of provision from school, (5, 17.24%)
  - ❖ Dissatisfaction with quality (i.e., parents more qualified, teacher qualifications and overall poor school quality, (4, 13.73%)
  - ❖ Lack of progress in child's overall development, (3, 10.34%)
  - ❖ Neglect or avoidance by students and/or staff, (2, 6.9%)
  - ❖ Desire for religious and moral based instruction, (2, 6.9%)
  - ❖ Multiple reasons, (2) 6.9%

- **Dr. Raymond Moore (2007)** took an additional approach to **public and home schooling**. He felt that parents should homeschool and delay sending their children to public schools until the child was between 8 and 12 years of age when the child is more mature (Basham, Merrifield, & Hepburn, 2007). This idea resounded with Christian Right ideologists with the publication of *Home Grown Kids* (1981) and *Home-Spun Schools* (1982) by Moore (Basham, Merrifield, & Hepburn, 2007).

### **Current Demographic Characteristics of Homeschoolers**

As of 2007, it was estimated by the **National Center for Education Statistics (2007)** that 1.5 million children in the United States were being homeschooled out of a total school population of 114.8 million children registered in playschool through 12<sup>th</sup> grade. More White students are homeschooled than African American, Hispanic students or students from other racial/ethnic groups (NCES, 2007). Students who are homeschooled are more likely to be in two-parent households, with one parent in the labor force (NCES, 2007). The majority of parents homeschooling children (97.9%) are married and have an average of 3.5 children, compared to the overall population average of 2.0 children (Ray, 2009). Homeschooler's median family income (\$75,000-\$79,999) closely spans the general median (\$75,000) for families regulated by a married couple with one or more children under the age of eighteen (Ray, 2009). The education levels of parents that homeschool can vary however, the majority of homeschooling parents having a bachelor's degree (Ray, 2009). In order to understand the context of homeschooling, it is important to note that the ability for a parent to homeschool is influenced by legislation and case law which will be discussed in further detail in the following section.

Of note, 6% of parents in the NCES 2007 survey chose to homeschool due to their child's special needs including learning disabilities, medical needs, and giftedness. Additionally, Chopp (2003) found that parents of children with special needs often chose homeschooling because they believed "the public school was not fulfilling the Individual Education Plan, providing the services parents wanted their child to have, or providing enough service" (Chopp, 2003, p.132). Parents also believed the public schools were not allowing children with special needs to progress at their own step, but rather forced children to progress at the step of a typical child (Chopp, 2003).

There is one study which was specifically conducted to explore special education instruction for children with special needs who are homeschooled (Duffey, 2000). Duffey's study consisted of 100 families of special needs children and collected data to analyze the reasons parents chose to homeschool a child with special needs. Parents were able to give multiple reasons for homeschooling. The study found that 62 of the 100 parents surveyed turned to homeschooling when conservative education failed to live up to their expectations. In addition, these parents felt that home was a more favorable environment. Duffey found that 27 participants chose homeschooling because it was consistent with family dynamics. For example, homeschooling matched the need for family time due to father's work schedule. Twenty-six parents chose homeschooling due to the desire to teach religious values and sacraments citing that public schools do everything they can to keep religion out of schools (Duffey, 2000).

- **Shubanhgi Vaidya (2008)**, in her research on "A SOCIOLOGICAL STUDY OF FAMILIES OF AUTISTIC CHILDREN IN DELHI".

Writing about siblings in a cross cultural perspective, Nuckolls (1993) points out that anthropological studies of siblingship have been light, on account of the preoccupation with rules of ancestry, and kinship studies based on generational and marriage structures. Western studies on sibling ship tended to focus on "sibling rivalry" deemed as a critical aspect in the formation of an adult identity based on competition.

- **Weisner ( 1993)** points out that sibling life in South Asia differs from that in North America as South Asian siblings participate in "shared activity settings" throughout their lives. The sibling relationship thus represents a powerful cultural image of an ideal social bond for which members of a culture should endeavor. The study can point out how Indian tradition valorizes the bond between siblings; the RamLakshman duet is illustrative of the loyalty and devotion focused on sibling bonds. The rapidly changing urban scenario against which this study is located manifests in family structures and systems. Family size is decreasing. Couples 'plan' their children and plan fewer of them. Families exhibit greater longitudinal and social mobility than before; children have to adjust to new neighbourhoods, schools, peer groups and social groups/ relations. The sibling

relationship thus assumes great significance; it embodies the permanence, steadiness and life-long character that other significant relationships are fast misplacing. Siblings provide each other with opportunities for sharing, expressing feelings, compromising, understanding mutual cooperation. They learn to play amongst themselves attached with social life .

A range of studies in the West has shown that having a brother or sister with a developmental disability has an impact on the progress and well being of both the **regularly** developing child and the disabled one. Birth order, sibling gender, severity of the disability and the socio-economic status of the family can directly impact sibling relationships. The presence of a child with special needs may frequently involve siblings in direct care-giving activities, controlling or pleasurable their brother or sister. The care-taking role is deeply in-built in older siblings in South Asia. In middle-class urban reserves where both parents work, it is fairly common to observe "latch-key children" who come back to an empty home, and telephonically inform the parents at work that they are safe. The older sibling is entrusted with the responsibility of supervising the younger one and ensuring that she/he keeps out of mischief until the parents return. The preference to send siblings to the same school and the familiar sight of siblings tightly holding hands on the way to the school bus stop and back home are part of our metropolitan landscape. While the preference for one child only is gaining currency with upwardly mobile elites, not having a sibling is regarded as a child's misfortune, particularly when extended-family networks are becoming loose and verbose.

- The study of **Powell and Gallagher (1993)** explored the common concerns and anxieties of siblings of children with special needs, including autism. Six general categories were identified:
- Concerns for the child: such as the cause and onset of the disability, availability of appropriate provision, the longer-term future.
  - Concerns related to parents: including the perceived differential expectations upon their behaviour and that of the sibling; communication with parents; anxiety about the pressure upon the parents' time.
  - Their own feelings: concern over the relationship with the disabled child; their own health.



- Suspicions about peer attitudes: how to deal with teasing; informing their friends about their sibling's needs; anxieties about gaining boy or girl friends.
- Community issues: getting on at school, acceptance within the wider neighbourhood.
- Future problems as adults: having to take up financial responsibility or custody; having to mediate with support services.

**Miller (2001.)** in his study concluded that there were excessively high levels of expectations forced upon normally developing siblings, particularly boys. Girls were company purposely or unpurposefully into the role of parent surrogate. Miller's own research, conducted through interviews with 24 children and their mothers, focused on their day-to-day activities with the autistic child, the difficulties in interactions between them, compensatory strategies, and parenting style. The results of the maternal reports suggested that sibling relationships were uniformly positive, with few feelings of jealousy or rivalry, a finding borne out by the present study as well, despite the difference in cultural setting. Miller also concluded the superiority of care-giving and helping activities performed by siblings of autistic children as compared to play-based interactions. Miller argues that there is a need for young children directly to be taught interactive skills in order to share more play-based activities with the autistic brother or sister.

**Kaminsky and Dewey (2002)** begins with a recognition of the frequency with which children with autism may engage in behaviours that appear aggressive, impulsive or obsessive and can thus disturb family life. The difficulties with communication, and anxiety surrounding family outings and public contact may present challenges not just to parents but also the siblings. The authors set out to investigate whether siblings of children with autism have greater difficulties in psycho-social adjustment than siblings of children with Down's syndrome or siblings of normally developing children. The results indicated that siblings of children with autism are not at greater risk for adjustment difficulties or loneliness. The authors guessed that this could be on account of their participation in support groups, thus leading to enhanced knowledge about autism and more frequent interaction with other families of children with autism. The social support resulting from such participation may facilitate healthy adjustment. This finding has significance for the present study

in the context of the participation of families in the activities of the NGO, which, as family provide siblings spaces to "be themselves" without constantly worrying about the autistic child's behaviours and what others think and feel of him/her.

### **Case Study: Charu's family**

Charu is a 10 year old girl with autism. She speaks a few words like "Maggi" and "toffee". She is hyperactive and wonder off here and there. She is tall, slim yet strongly built, with curly cropped hair and a beautiful smile. She is the first child of Rani and Gurvinder. Shalini her cousin, (father's brother's daughter) was a 19 year old college student when she was born, and the new baby was her "toy". Shortly after Cham's birth, Rani conceived again. It was a difficult pregnancy and she was advised bed rest. Cham's care fell to Shalini, a responsibility she accepted joyfully. Although her motor milestones were normal, she had delay development in speech, and by the age of three, her insufficiencies became specious. She was diagnosed autistic after almost a year of doctor's visits during which she would be accompanied by her father and Shalini. The realization that it was a life-long condition came as a great shock to the family.

Gurvinder suffered from extreme depression and Rani withdrew from the child. Shalini, at 23 was now Cham's surrogate mother and companion. She quit college and devoted herself to the care of the little girl. Shalini reports that she hates the atmosphere at home totally uncomfortable. It is noisy, quarrelsome and disorganised. She is an orphan, her grandparents are old and weak. Rani refuses to take responsibility for her daughter and spends much of her time visiting her natal home.

The younger brother and his wife resent Shalini's involvement with Gurvinder's children. They have instructed their own children to insult and slender their cousin at the slenderest excuse. Shalini often loses her temper and slaps them, leading to fights. She vents her anger and frustration onto her grandmother who listens apathetically and without response. Once or twice she even suggested Charu when she urinated in the neighbour's house. The look of fear on the child's face made her feel so guilty, she execrated to herself she would never hit her again. She has fights with the neighbours who call Charu *paagal* and *bewakuf* (mad, stupid) because she is in the habit of throwing things into their terraces, collecting toothbrushes from their houses and

urinating on the common staircase. When they slight the child, Rani shouts at them, but soon forgets and becomes friends again. Mehek is very attached to and protective of her elder sister, and will only do her homework if Shalini and Charu sit down with her. Rani resents the "hold" Shalini has over her regularly developing daughter. Shalini is now 30. Thin and pale-skinned, she wears simple, old fashioned *sa/war kameez*, and pulls back her curly hair in a severe pony-tail. She has lost touch with all her friends after leaving college, and misses her parents greatly. No-one in the family seems to be interested in arranging her marriage. She says. " . . I have stopped thinking about marriage .. what will happen to Charu then? if people in the family, if her own mother is not ready to do things for her, why will any outsider bother?" She knows that as long as her grandparents are alive, she will be looked after and protected. But she is not sure about what the future holds for her. Will she be considered a burden? Or will she have to "earn her keep" by assuming continued responsibility for the disabled child? She does not know the answers.

### Summary And Conclusions

The thesis aimed to explore the manner in which a group of families living in Delhi negotiated with autism, the neuro-developmental disorder that suffering their children. The study designated and to analysed the manner in which they understood this complex disability, attended to the special needs of the autistic child and prepared themselves for the prospect of life-long care and an uncertain future. Contemporarily, they carried on with the other activities and responsibilities that domestic life requires, including earning a living, taking care of the physical and psychological needs of other children, aging parents other family members, conjugal life, maintaining hereditary and friendship networks, professional obligations, etc. In other words, our description and analysis of disability management on the part of the family is implanted within the daily ness and routine schedule of domestic life.

- **Kristen N. Kelley(July 2008)**, in his study on “EFFECTS OF SIBLING TRAINING ON IN-HOME APPLIED BEHAVIOR ANALYSIS PROGRAMS AND ATTITUDES TOWARD CHILDREN WITH AUTISM”.

The purpose of this study was to investigate the effectiveness of a training program designed for siblings of children with autism. The training program attempted to

educate siblings about autism and teach them some skills they may be able to use when interacting with their autistic brother or sister. In addition this training attempted to improve the attitudes of the siblings toward children with autism.

## **RESULTS**

### ***Sibling Survey Responses***

The individual responses of each of the four siblings on each of the ten items on the Sibling Survey at pretest, posttest, and follow-up are presented . The means and standard deviations for each item at pretest, posttest, and follow-up are presented ‘ While some of the item means tend to show higher values at posttest or follow-up than at pretest, repeated-measures analysis of variance followed by orthogonal disparities did not show any significant changes in the siblings’ mean responses, from pretest to posttest or from pretest to follow-up, on any of the items. Total Sibling Survey scores for each sibling were also calculated by summing the sibling’s item scores. The ten items were positive in their response, such that higher numbers on the Likert scale represented more adaptive sibling responses. (The internal consistency or inter-item reliability, as measured by Cronbach’s alpha on the standardized items, while small at pretest ( $\alpha = .354$ ), was high at posttest ( $\alpha = .865$ ) and at follow-up ( $\alpha = .852$ ). Thus, the Total Sibling Survey score was included as a measure of overall sibling adaptation.)

The Total Sibling Survey Repeated-measures analysis of variance with orthogonal contrasts did not show a significant change in mean Total Sibling Survey score from pretest ( $M = 37.75$ ) to posttest ( $M = 39.75$ ) and follow-up ( $M = 36.75$ ).

The effects of sibling training on maladaptive behavior of children diagnosed with autism were inspected before and after a one-day workshop on behavior therapy and autism. In addition, siblings’ attitudes toward the autistic child before and after the training were examined. Courses included basic principles of applied behavior analysis and separate trial training, as well as basic education on what autism is and the variety of ways it may manifest itself in an individual. Parent training is believed to provide the child diagnosed with autism with non-therapeutic relationships that have greater similarity to the therapeutic environment, resulting in greater steadiness

in behavior change and more effective treatment. It was therefore hypothesized that similar results would be found after training of siblings. Furthermore it was hypothesized that the additional effect of an improved attitude toward the autistic child would occur, thereby increasing the likelihood of positive and constructive interactions between the sibling and the autistic child. The training workshop was administered to siblings of children with autism who are currently receiving in-home behavioral support. The training group consisted of 4 siblings ranging in ages from 8 to 14 years. Two groups of two siblings each were formed based on age level and participant availability, in one training pairing two siblings that are close in age, and in the other training pairing two siblings from the same family. Using a multiple-baseline design, two training sessions were directed at different times, one for each set of two siblings. It was hypothesized that the sibling training would demonstrate that when siblings are provided with information and skills in the area of behavior analysis and autism, their attitudes toward autistic children would become more positive, they would interact more frequently and positively with their autistic sibling, and the frequency and greatness of maladaptive behavior exhibited by the autistic child would decrease. A further implication of this study is that sibling training will assist in further success of in-home behavioral support plans and in the creation of behavioral programs and action plan for the further modules.

- **Jonathan Wilkins (August 2010), “THE RELATIONSHIP BETWEEN SOCIAL SKILLS AND CHALLENGING BEHAVIORS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS”.**

Data were collected to determine the psychometric properties of the ASD Battery (e.g., Matson, González, Wilkins, et al., 2008). Parents and other caretakers (e.g., grandparents) of children with and without developmental delays were recruited to participate in the original study. Participants were recruited from a variety of locations, which included centers specializing in developmental disabilities, parent support and advocacy/ community groups, outpatient clinics, and professional and participant-referrals in the following states: California, Connecticut, Georgia, Maryland, Michigan, Mississippi, New York, North Carolina, Texas, Mississippi, and Louisiana. Recruitment sites also included public and private fundamental schools in Louisiana. The majority (90.3%) of data collected was from Louisiana. Because

children were recruited from several different locations and methods of diagnosis may vary between positions, group assignment was made based on a checklist of combined DSM-IV-TR and ICD-10 criteria for ASD (see below for more information). More specifically, to be included in the ASD group, an certification of at least three symptoms on the checklist was required (two deficits in social interaction and one in another area of functioning, either communication or repetitive/restrictive behavior). Such a symptom pattern parallels to a DSM-IV-TR diagnosis of PDD-NOS, the ASD with the least stringent diagnostic criteria (APA, 2000). One hundred and fifty-three (55.8%) children met criteria as an ASD participant in the study, while 121 (44.2%) did not meet the research criteria for having an ASD, nor did they have any other psychopathology noted by the informer. Mean total item endorsement on the DSM-IV-TR/ICD-10 checklist for the ASD group was 11.56 (range = 3-19), whereas the mean for the 65 control group was 0.46 (range = 0-5). Children who did not meet research criteria for ASD and had a previous diagnosis of other psychopathology or developmental delay were excluded from the study.

Four participants were excluded due to missing data (i.e., more than 5% of the MESSY) and 19 participants were excluded due to missing questionnaires (either ASD-BPC or MESSY), thus a total of 251 ratings of children remained for data analysis. All other missing data were imputed with the mean score for that particular item for the child's group (ASD or control). The following data reflect those who remained in the database after excluded cases were removed.

The participants ranged in age from 3 to 16 years, with an average of 7.81 years. Results of an independent *t*-test indicated that the groups did not significantly differ in terms of age. Two hundred children (79.7%) were White, 21 (8.4%) were Black, 10 (4.0%) were Hispanic, 7 (2.8%) were of another ethnic background, and 13 (5.2%) were of unidentified ethnicity. Chi-square analysis indicated that the groups did not significantly differ in terms of ethnicity. One hundred and fifty-nine children (63.3%) were male and 92 (36.7%) were female. Results of a chi-square analysis revealed that there were significantly more males in the ASD group than in the control group,  $\chi^2(df = 1, N = 251) = 22.26, p < .001$ .

One hundred and twenty-nine (51.4%) informants indicated that the child had one or more previous diagnoses given by a mental health/medical professional at the time of

the study. All but one of these children was in the ASD group; the diagnoses indicated for this control were Dyslexia and Dysgraphia. The diagnoses reported for the ASD group were as follows: Autistic Disorder, Asperger's Disorder, PDD-NOS, ADHD, Anxiety Disorder-NOS, Apraxia, Asthma, Bilateral Hearing Loss, Bipolar Disorder, Cerebral Palsy, Depression, Developmental Delay (unspecified), Down's syndrome, Dyslexia, Dyspraxia, Fragile X syndrome, Generalized 66

Anxiety Disorder, Hyperactivity, Hypersomnia, Hypotonia, Impulse Control Disorder, Iodine Deficiency Disorder, Microcephaly, Nocturnal Enuresis, Nonverbal Learning Disorder, OCD, ODD, Panic Attacks, Psychosis-NOS, Receptive/Expressive Language Disorder, Selective Mutism, Sensory Integration Disorder, Social Phobia, Specific Phobia, Tic Disorder, and Tourette's syndrome. One hundred and seven (42.6% of the entire sample, 81.1% of the ASD group) children were reported to have some form of ASD (i.e., Autistic Disorder, Asperger's Disorder, or PDD-NOS), and twenty-four of these children also presented with a comorbid mental health condition (range = 1-4). Eight children were identified by their informants as having ID (all eight children met criteria for the ASD group). Sixty-one (24.3%) children (58 were in the ASD group) were prescribed some form of psychotropic medication (Antidepressants, Antipsychotics, Anxiolytics, Mood Stabilizers/Anti-Epileptic Medications, and/or Psychostimulants) at the time of data collection. Seven children (2.8%) were identified as having seizures or epilepsy, and one child (0.4%) was identified as being confined to a bed or wheelchair; these eight children all met criteria for the ASD group.

## **IMPLICATIONS AND FUTURE DIRECTIONS**

To summarize, in Study 1 it was demonstrated that the relationship between social skills and challenging behavior was more pronounced for children and adolescents with ASD compared to their typically developing peers. Additionally, it was shown that social skills deficits/excesses predicted the presence of certain challenging behaviors in these individuals. The results of Study 2 revealed that social skills deficits/excesses predicted the presence of challenging behavior (internalizing and total problem behavior scores) above and beyond levels of ASD symptom severity.

The results of these analyses contribute to our knowledge of the behavioral presentation of ASD by extending the results of previous research with adults (i.e., Matson et al., 2009) through an examination of the relationship between two salient features of ASD (social skills deficits and challenging behavior) in children and adolescents. This study also represents a promising first step in understanding the contribution of other factors to this relationship (i.e., ASD symptom severity, age, and gender). However, the sample consisted of only a slight division of individuals with ASD and thus the generalizability of the results to other samples and groups of persons with ASD is therefore unknown.

Further, the nature of the data collection procedures prevented the sample from being random, which decreases the likelihood that the findings are representative of the total population. Many of the children in the ASD group were recruited from outpatient clinics specializing in the treatment/assessment of ASD and related difficulties. As mentioned earlier, the majority of the sample was recruited from Louisiana (90.3%) through outpatient clinics, participant and professional referrals, support/advocacy groups, and schools. It is possible that some participants self-selected to participate in the study for reasons such as obtaining professional feedback or additional services for their child. Additionally, the majority of the sample consisted of children from upper-middle class families. An ideal sample would comprise children randomly selected from the population and equally distributed across SES and location. Practically speaking, such a sample is rarely, if ever, achieved in this type of research. However, replicating the study across different samples and demographic groups would help remedy questions about the generalizability of the results. Although the demographic homogeneity of the sample is a limitation, the sample size of 132 children with ASD represents an overall strength. For example, published studies examining symptom profiles of persons with ASD rarely obtain sample sizes greater than 50.

It should also be mentioned that informants were not blind to the purpose of the original study (i.e., developing a new assessment measure for children with autism) and this knowledge may have influenced their responses. The informants were aware that they would be receiving recommendations based on the results. There exists the possibility that informants may have inflated or deflated their endorsements based on



previous knowledge of ASD as opposed to their actual observations of the child being assessed.

Another major limitation of the sample was the manner in which group assignment was made. Because the study utilized an archival database, group assignment had already been determined. The rationale for the method of group assignment is as follows. Because the database consisted of participants recruited from multiple locations across the United States, the method of diagnosis more than likely differed from site to site. In order to ensure consistency of diagnoses, a checklist was created to identify those meeting criteria for an ASD.

However, the use of such a checklist is problematic for several reasons. For example, in most cases the diagnoses were not confirmed, and thus, relied entirely on parent report. As such, there may have been instances where parents were over-reporting symptom severity in an attempt to get services for their children. Secondly, the group assignment procedures were not very stringent and thus the ASD group was somewhat heterogeneous in terms of symptom severity. Additionally, children with previous diagnoses of the three ASD were included with children who had been diagnosed with other mental health conditions as well as those having no previous psychiatric diagnosis. The results may have been stronger if only more severe cases had been included in the sample. Likewise, the checklist did not differentiate among ASD and more than likely included a mix of the three most common ASD (i.e., Autistic Disorder, PDD-NOS, and Asperger's Disorder). Altogether, although differential diagnosis can be challenging in some cases and some children in the sample may have never been formally assessed, this issue still limits the generalizability of the findings.

As such, future studies should employ more rigorous forms of diagnosis and compare groups within the ASD diagnostic umbrella to allow for a more fine-grained analysis. For example, the relationship between social skills and challenging behavior could be compared across the three most common ASD mentioned above. To achieve such a research design, group assignment should be made based on the results of a standardized diagnostic workup in which each participant was individually assessed using more conservative and difficult measures of ASD such as the ADOS-G and ADI-R in conjunction with examination by a licensed psychologist. Additionally,

reliability of diagnoses should be obtained in such a study. It would be presumed that the relationship between challenging behavior and social skills would be less pronounced in those children with PDD-NOS compared to Autistic Disorder, given that symptoms of social impairment are likely to be more severe in those with Autistic Disorder and research indicating that for adults with ASD, those with this diagnosis exhibit higher rates of challenging behavior compared to those with PDD-NOS (Matson & Rivet, 2008). Additionally, it would be useful to utilize other comparison groups, such as children not meeting criteria for ASD but presenting with other psychiatric difficulties or ID.

- **Tiffany Wiggs( 2010)**, “Stress Levels and Development: A Phenomenology of Autistic Children and Their Parents”.

### **Abstract**

Being a parent means taking on both the joys and struggles that come with it. When a parent discovers that his or her child has been diagnosed with autism spectrum disorder (ASD), the level of stress changes. It could be helpful to discover the severity of change that the stresses involved in parenting a child with ASD brings to the parent/child relationship and what effect this has on a child’s physical, cognitive, emotional, and spiritual development. To attempt to answer these questions, six parents were interviewed. Findings suggested that structure in daily living improves the quality of the child/parent relationship as well as stress relief to the parent.

### **About Autism Spectrum Disorders (ASD)**

**Symptoms.** The number of children that have been diagnosed with Autism Spectrum Disorder (ASD) has increased and is continuing to do so at a rapid rate (Pottie & Ingram, 2008). The Center for Disease Control and Prevention (CDC, 2010) currently estimates that about 1 in 110 children in the United States have an ASD. ASDs also appear to be diagnosed in at least 1 in 600 individuals, of all age, and about 1 in 200 children show at least some symptoms of it. It has been described as a social disorder in which an individual has severe and pervasive impairments in the development of social interaction (Rutgers et al., 2007). These types of disorders are also defined as a group marked by unusual communications and inappropriate responses to stimuli in the environment (Comer, 2008). Its symptoms may begin to show before the age of 3.

Parents may notice their infant or young toddler exhibiting a loss of focus, lack of eye contact, repetitive behaviors, rigidity, and/or delayed motor abilities. (Boyd, McBee, Holtzclaw, Baranek, & Bodfish, 2009; Dubin & Graetz, 2009). These symptoms are what distinguish a child with autism from a neuro typical, or normally developing child (Broderick & Ne'eman, 2008). Once a parent or guardian has recognized some of these symptoms, the child is typically taken in for an assessment, which is often followed by a diagnosis.

➤ **Jenkins (2007) described** autism this way:

Imagine what it's like. A person smiles at you—you're confused because you don't understand a smile. You can't get your usual breakfast cereal—your whole day is in confusion because you can't cope with your routine being upset. And someone tells you to pull your socks up. But you know you're not wearing socks, and it's very bewildering.

**Diagnoses.** An ASD is usually diagnosed in individuals around the age of 3 or 4 years old and has a variety of possible diagnoses. The ASDs are autistic disorder (or autism), Asperger's syndrome, and pervasive developmental disorder.

Autistic disorder is characterized by impairments in the areas of social interaction and communication. Individuals with this disorder typically express repetitive behaviors and abnormal behavior patterns. However, individuals with Asperger's syndrome show some autistic behaviors including delayed motor abilities and very literal interpretations.

However, individuals with this disorder may have an advanced vocabulary while exhibiting difficulty socially interacting with others (Dubin & Graetz, 2009). Pervasive developmental disorder is diagnosed when symptoms of autism are present but do not meet the criteria to qualify the child as having autistic disorder (King, 2009). These disorders, until recently, have always been considered to be childhood disorders.

However, more recent research has found that these disorders persist through childhood, adolescence, and even adulthood (Matson & Shoemaker, 2009).

**Causes.** The cause of autism is currently unknown, creating polemic on the topic. Theorists initially believed that autism is caused by family dysfunction and social stress (Comer, 2008). However, research has shown that stress and dysfunction alone cannot cause a disorder as complex as autism (HHS, 2009). There are multiple opinions regarding possible causes including vaccinations and genetics.

**Vaccinations.** A possible link between autism and childhood vaccinations is popular and controversial. However, scientific studies have not conclusively identified the links between autism and either thimerosal-containing vaccines or the measles, mumps, and rubella vaccine. The debate over this topic is controversial because the link between ASD and childhood vaccinations is very unclear. However, research has found the link between autism and childhood vaccinations to be correlational (Wakefield, 1999). The number of autism cases has increased over the past several decades. However, it is not clear whether or not this is due to an actual increase in the appearance of the disorder, an increase in awareness, or differences in the methods used to assess occurrence of the disorder (Miller & Reynolds, 2009).

**Genetics.** The study of biological causes of Autism is still under research.

However, it has been found that there is an increased risk for siblings of those with ASD to also manifest the disorder (Aneja & Tierney, 2008). The National Institute of Health (HHS, 2009) suggested that the genetic link to autism is complicated and stated that, “In most cases, it’s likely that each gene contributes a small amount of risk, and interacts with other genes and environmental factors to trigger the onset of the disease.”

**Cures and treatments.** Although there is currently no defined cure for autism, there are many kinds of treatments available. There is a great need for intervention among children diagnosed with ASD. Although there are many interventions currently being used and developed, there is still a need for more. One type of treatment is a classroom-based antecedent intervention in which the child is given structured opportunities to use preferred leisure activities (Sigafoos, Green, Payne, O’Reilly, & Lancioni, 2009). The symptom that is given attention by this type of treatment is obsessive-repetitive behavior. Some current therapies use evidence-based medicine.

This emphasizes the areas of information processing, neural connectivity, and organization.

The developers of these types of treatment believe that autism is defined as a biological disorder, with a focus on the genetics, neurochemistry and neuro anatomy areas in autism (Zimmerman, 2008). The most common treatment program used for autism is called Applied Behavior Analysis (ABA). Many families choose to use a combination of treatments with this program, including auditory integration, diet, facilitated communication, and sensory integration (Schreck & Mazur, 2008). B.F. Skinner formulated the concept of behavior analysis. The idea of positive reinforcement for a behavior is often used. The main goal of therapies for individuals with autism is to assist the autistic individual in functioning independently and in all types of environments (*Be Informed*, 2010).

Some other types of treatments that are popular today are gluten-free casein-free diet (GFCF), occupational therapy, sensory integration therapy, speech therapy, verbal behavior intervention, floor time, relationship development intervention, Picture Exchange Communication System (PECS), Social Communication/ Emotional Regulation/ Transactional Support (SCERTS), and Training and Education of Autistic Related Communication Handicapped Children (TEACCH). Floor time is when the parent or mentor meets the child where they are at physically and socially, follows his or her lead, and gets involved with the child's activities. It is as if the parent is trying to get into the child's *world* and understand it from his or her point of view. Those who choose

to put their child on a gluten-free casein-free diet keep a focus on the fiber and vitamin intake in his or her diet. Occupational therapy focuses on social play and functioning.

Some of the areas of development that are given particular attention with this therapy are coping skills, fine motor skills, play skills, self-help skills, and social skills. These therapies are all techniques that are sometimes used in the assistance of a child's proper development and social advancement (Autism Speaks Inc., 2010). Research has also found that about 50 percent of children with autism use treatments including vitamin supplements, magnesium, gastrointestinal medications, antifungal agents,

vitamin C, secretin, chelatoins, immunoglobins, large doses of vitamin A, antibiotics, antiviral agents, alkaline salts, withholding immunizations, auditory integration training, interactive metronome, craniosacral manipulation, and facilitated communication (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003).

Intervention for a child with autism is imperative and most effective when done as early as possible into the child's diagnosis (Goin, 2003). This has been shown to promote further progress in a child with autism. Some of the aspects of the child's development that may be positively affected by early intervention and therapy are intelligence quotient (IQ) score and improvement in cognitive, language, and adaptive behaviors. Even with such early intervention only approximately fifteen percent of individuals with ASD are self-sufficient as adults (Bopp, Mirenda, & Zumbo, 2009). It is especially difficult to find the most effective therapy for a child with autism, because there are so many available and each individual with autism is unique, having multitudes of sensory needs that are characteristic of that individual.

- **Sarah Elizabeth Hall (August 2011)**, “ Factors Affecting Parents’ Decisions to Treat Their Children With Autism Spectrum Disorder With Complementary And Alternative Treatments”.

As stated previously, autism affects approximately one in 150 children in the United States [Centers for Disease Control and Prevention (CDC), 2007]. The classic features are abnormal or impaired development in social interaction and communication, in combination with a severely regulated collection of activity and interests (American Psychiatric Association [APA], 2000). Children with autism also may display degrees of repetitive and stereotyped behaviors (APA, 2000) that are manifested in various ways, depending on the child and the level of impairment. The term autism spectrum disorder (ASD), also known as pervasive developmental disorder, encompasses five different disorders: Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett’s Disorder, and Childhood Disintegrative Disorder (American Psychiatric Association [APA], 2000). It seems that many parents turn to complementary and alternative treatments for their children with autism. In one study, 74% were using complementary and alternative medicine for their child with ASD (Hanson et al., 2007). There is also little information about the frequency of use of these strategies and the characteristics associated with their use (Levy et al.,

2003). Complementary and alternative (CAM) treatments can be used alongside (complementary) and as a substitute (alternative) for conventional treatments (Hyman & Levy, 2005).

#### Complementary and Alternative Treatments (CAM)

- CAM treatments are either biologic or non- biologic (Levy & Hyman, 2002). Based on the organization of Levy and Hyman (2005) and Zimmer and Molloy (2007), CAM treatments can be divided into five general categories, with some treatments overlapping: digestive and immune treatments, treatments aimed at modulating neurotransmitters and neuropeptides, treatments that target impaired methylation capacity, heavy metal treatments, and non- biological interferences.
- Results indicated a statistically significant relationship between severity of symptoms with having tried treatments in the past, and with currently using treatments. Treatments tried in the past that were correlated with greater severity of symptoms included: Gluten-Free/Casein-Free diet (.16,  $p \leq .001$ ), Secretin (.21,  $p \leq .001$ ), Omega-3 Fatty acid supplements (.16,  $p \leq .001$ ), Probiotics (.13,  $p \leq .01$ ), Glutathione (.12,  $p \leq .01$ ), Specific Carbohydrate diet (.09,  $p \leq .05$ ), SAM-E (S-adenosylmethionine) (.12,  $p \leq .05$ ), and Melatonin (.10,  $p \leq .05$ ). Treatments that were currently being used that were correlated with greater severity of symptoms included: Facilitated Communication (.13,  $p \leq .01$ ), Melatonin, (.11,  $p \leq .05$ ), and Sensory integration therapy (.10,  $p \leq .05$ ). Interestingly, current use of Omega-3 Fatty Acid supplements (-.10,  $p \leq .05$ ) had a negative relationship with severity of symptoms, while previous use of Omega-3 was positively correlated with greater severity of symptoms. In addition, it was noted that no one endorsed ever having used D-Cycloserine. Severity of symptoms was not predictive of the total number of CAMs used.
- It was hypothesized that there would be multiple barriers to treatment. Results for each of these potential barriers were calculated and are presented in Table 8. Based on responses, 78.1% of respondents indicated a belief that autism was not curable, while 20.1% indicated a belief that autism is curable. When asked to rate the level of difficulty to obtain information about treatments, a majority of respondents (42.5%) indicated that it is “somewhat hard” to obtain information, while 25.9% indicated that it is “not hard” to obtain information, 17.9% indicated

that it is “hard” to obtain information, 8% indicated that it is “very hard” to obtain information, and 5.1% indicated that it is “extremely hard” to obtain information.

- Regarding overall experience with the healthcare system, a majority (39.8%) indicated having had a “good” overall experience. 29% of respondents indicated a “bad” overall experience, and 13.1% indicated a “very bad” experience. 15% indicated a “very good” experience, and 1.8% indicated an “extremely good” experience. In addition, the respondents indicated consulting with an average number of 4.1 medical professionals ( $SD = 5.89$ ) when seeking a diagnosis for their child.

## **CONCLUSIONS**

The purpose of this study was to examine factors that contribute to parents’ decisions to treat their child with ASD using a complementary or alternative treatment. In order to determine this, an online survey was developed, and invitations to participate were sent to approximately 800 support groups for parents of children with autism. Results from 452 respondents indicated that a statistically significant relationship existed between severity of symptoms with having tried treatments in the past, as well as with currently using treatments.

Overall, the responding parents/guardians were mothers, fathers, and grandmothers with a mean age of 41.58. The majority self-identified as White (86.7%), with a majority having attained a college education (41.8%) and of moderate income (\$89,106.66). 100% of the participants in the study indicated they had tried a CAM in the past, or were currently using one.

### **Severity and CAM Treatment**

Treatments tried in the past that were correlated with greater severity of symptoms included: Gluten-Free/Casein-Free diet, Secretin, Omega-3 Fatty acid supplements, Probiotics, Glutathione, Specific Carbohydrate diet, SAM-E (S-adenosylmethionine), and Melatonin. Treatments that were currently being used that were correlated with greater severity of symptoms included: Facilitated Communication, Melatonin, and Sensory integration therapy.



➤ **Margot prior, The University of Melbourne, Jacqueline M.A.Roberts, Griffith University, katrina Williams, University of Melbourne & The Royal children's Hospital(2011), “ A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders”.**

- The study reveal a stronger emphasis on the need for service providers to meet good practice standards, particularly in the areas of multi-disciplinary practice and family involvement.
- Stakeholder feedback also included concerns about lack of experience and expertise among service providers. The review team recommended stronger requirement for personnel to demonstrate substantial autism experience and expertise, for FaHCSIA to be informed of any changes to the staff skill and experience profile, ongoing scrutiny of training qualifications, and engagement of providers in relevant professional development.
- According to survey by FaHCSIA
- Samples were 28 parents.
- **Professional background:**
- 32% engaged in Teaching Profession, 29% in Psychology Background, 46% engaged in other i.e. O.T., Speech Pathology, Social Work, and some of are engaged in more than one Profession.
- **Evidence based Intervention:**
- 57% are well evidenced, 36% are adequately evidenced, Only 4% are very well evidenced and 4% are inadequate evidenced.
- **Parent's Needs:** 100% parents need Information about services available 86% need information about accessing right services.
- 82% need Information about ASD, While 79% need Emotional Support and information about parent support groups.

#### **Evaluating and managing service provider applications**

- The reviewers recommended a review and tightening of current procedures for assessing service provider applications with a focus on additional details on personnel, proposed interventions and how they will deliver best practice.

Changes to the application form are suggested that will enable improved collection of information to assist with this assessment.

- They also provided a ‘script’ for FaHCSIA staff when responding to enquiries from potential providers which draws attention to the rationale, key elements, and current status of effective interventions for children with ASD.
- **Role of Autism Advisors :**
- It was recommended that the role of Autism Advisors be expanded to include brokerage advice and support for families.
- **Ongoing monitoring and evaluation of services**
- The Review identified stakeholder concerns about a lack of monitoring of service providers once they are on the Panel. Recommendations include:
  - Ongoing monitoring by FaHCSIA
  - Regular reporting to FaHCSIA encompassing reports of progress of children towards the stated goals of their intervention
  - Accountability of funding through on-site visits, questionnaires or parents surveys
  - Monitoring and follow-up of provider programs to ensure fidelity of treatment

Clarify and promulgate clear and consistent fee schedules.

- **Neeraja Ravindran, Virginia Commonwealth University, Mumbai ( 2012),**  
“PARENT AND PROFESSIONAL PERSPECTIVES ABOUT AUTISM SPECTRUM DISORDERS IN SOUTH INDIA: BELIEFS, PRACTICES, AND PARENT-PROFESSIONAL RELATIONSHIPS”.

The purpose of this qualitative study was to examine the experience of parents and professionals living in a large metropolitan city in South India who were raising and/or working with a child with an autism spectrum disorder. The study explored the unique perspectives of parents and professionals regarding their beliefs and practices about autism, as well as the nature of the parent-professional relationship. Nineteen parents (all mothers) and 21 professionals were interviewed in person at four schools, an early intervention program, a hospital clinic, and a physician’s office.

The meaning of health, illness, and disability vary greatly across cultures and across time. Bronfenbrenner's ecological model provided the conceptual paradigm to examine how broad cultural beliefs in the macro system, local services in the ecosystem, parent- professional relationships in the mesosystem, and practices at home and school in the child's microsystem worked together to explain autism spectrum disorders for this group of participants at this point in history.

Four major themes emerged from the study that related to parents' and professionals' beliefs about causes of autism, expectations from treatments and services, nature of parent professional partnerships in managing a child's autism, and the current 'state of things' with regard to autism in one South Indian city. Across the themes, parents and professionals embraced two superficially conflicting yet perfectly compatible cultural beliefs: a modern, scientific approach and a traditional Indian viewpoint. The treatments offered to children were similar to Western practices, with the addition of traditional Indian practices (e.g., yoga, Ayurvedic medicine, Siddha). Parents were mostly happy and comfortable with their interactions with the professionals. Parents valued collaboration and respect but also acknowledged that the relationship was vertical in nature, with professionals having more authority. Professionals' assessment of their relationship with parents was influenced by their overall views about the families—positive or negative—which in turn was influenced by what they believed caused the child's autism (e.g., genetics/scientific causes vs. cold parenting and departure from traditional family structure). Services for children with autism in India are rapidly expanding, though the vast majority of those affected are not diagnosed or treated.

Qualitative coding of the parent and **professional** interviews ( $N=40$ ) generated 10 broad categories and a cluster of 57 codes across categories representing themes that emerged from the data. Of the 10 categories, five were common to both parents and professionals (Beliefs about Causes, Decision-making about Treatments, Implementation of Treatments, Parent-Professional Relationship, and Autism in India), two were exclusive to parents (Satisfaction with Treatments and Services and Expectations for Child's Future), and three were exclusive to professionals (Report of Family Beliefs about Causes, Report of Family Expectations for Child's Future, and

Views about Families). The coding clusters under each category represented descriptive themes of parents' and professionals' beliefs about autism (e.g., Don't know or Unsure; Genetics; Religious and Spiritual Explanations etc.), nature of parent-professional relationships (e.g., Positive, Collaborative, Trusting, and Open; Ambivalent or mixed; Directive, Professional driven etc.), and the positive and negative processes and contextual factors associated with raising and/or working with a child with autism in South India (e.g., Society is understanding and supportive; Society is rejecting and critical; Problems with resources, expenses, and accessibility etc.). In addition, a separate category was created to account for the descriptions provided by both the parents and the professionals of treatments and services currently used with the children.

However, in the following sections, this category is treated descriptively and in terms of frequency (e.g., how many people report using what kind of treatments) rather than thematically, since we did not observe any of the treatments being implemented with the children, and thus cannot describe in context or in any detail what these treatments were and how they were implemented.

Across the 10 categories, each theme was mentioned by at least 25% of the individuals interviewed (range 5 to 18 parent sources and 5 to 20 professional sources per theme). Seventeen themes were mentioned by over half of the participants, and 11 themes were mentioned by at least 75% of the participants.

➤ **KAMEI, (2013)** Ph.D. Perceptions and Experiences of Mothers who have Children with Autism Spectrum Disorders: Cross-Cultural Studies from the US and Japan.

- **Rationale of the study:**
- The purpose of this study is to explore and understand the differences or similarities in maternal experiences and perceptions in regard to their children with Autism Spectrum Disorders (ASD) between the United States and Japan. A significant area of the study is that it focuses on mothers of children with ASD in cross-national settings.
- **Samples:**

- Samples in this study were 47 American and 49 Japanese mothers of elementary school age children with Autism Spectrum Disorders (ASD). The inclusion criteria for being American or Japanese was set as being non-immigrant. The elementary school age was defined to be between the ages of 5 to 12, which covered elementary school years in both countries (K to 5th grade in the US and 1st to 6th grade in Japan).

**Description of Participants** A total of 96 mothers of children with ASD participated in this study. In all 47 (48.9%) were recruited from North Carolina in the US and 49 (51%) were from Osaka, Japan.

- Their ages ranged from 29 to 54 years (US) and 31 to 52 years (Japan). Ethnicities of the US mothers were 33 White (72%), 10 Black (22%), and 4 Latino (7%), while ethnicities of Japanese mothers were 48 Asian (98%). There were significant differences among groups on demographic variables of their highest level of education, employment status, religious affiliation, and family income.
- A majority of the US mothers graduated from university (34%) or graduate school (55%), while a majority of Japanese mothers' highest level of education were some college or below (75%).
- None of the Japanese mothers graduated from graduate school. Also, a majority of the US mothers (77%) were employed outside of the home, while a majority of Japanese mothers (73%) were not employed outside of the home.
- Religious affiliation was also significantly different between the two groups : 38 mothers from the US (80.9%) were religious, and 33 of them (70%) were Christian; 44 Japanese mothers (89.8%) did not have any religious affiliation. Their child with ASD included 83 boys (86.5%) and 13 girls (13.5%): 44 boys (94%) and 3 girls (6%) from the US and 39 boys (80%) and 10 girls (20%) from Japan.
- 22 Children of the US participants (46.8%) and 9 Japanese participants (18.4%) were diagnosed as high functioning autism including Asperger's without having cognitive impairments., 23 (48.9%) children in the US site and 15 (30.6%) children in Japanese site had Autism.
- 25 (51%) of Japanese children were diagnosed as either having severe case of autism and moderate to severe intellectual disabilities. Finally, 27 US children (57%) with ASD went to regular classroom in public or private schools (24:

public school, and 3: private school), 43 (88%) Japanese children with ASD went to special education classrooms in regular public school or special education school. Only 6 (12%) Japanese children went to regular classrooms in a public school.

- **Abdulhade I. Haimour<sup>1,\*</sup> & Yahia F. Obaidat<sup>11</sup>**Department of Special Education, King Abdulaziz University, Saudi Arabia \*Corresponding author: Department of Special Education, King Abdulaziz University, Saudi Arabia, (August 2013), “School Teachers’ Knowledge about Autism”

The purpose of this study was to find out what school teachers know about Autism. In addition, this study attempted to find out if there any significant differences in school teachers’ knowledge about Autism depending on teachers’ (gender, position, education level, teaching experience, and contact with students with Autism) variables. A total of 391 general and special education teachers from various segregated and inclusive schools within the Jeddah in Saudi Arabia completed study instrument (*Autism knowledge Questionnaire*) to determine their level of knowledge about Autism. An analysis of the collected data, using descriptive statistics and analysis of variance, indicated that school teachers had an acceptable approaching to weak level of knowledge about Autism disorder. The results also indicated significant differences in the teachers’ knowledge about Autism depending on teachers’ (position, education level, teaching experience, and contact with students with Autism) favoring special education teachers, more advanced level of education and teaching experience, and those with previous contact with students with Autism.

## **1. Introduction and Literature Review**

Autism is a pervasive developmental disorder, characterized by communication insufficiencies, social interaction deficiencies, and restricted or repetitive behaviors and interests ([DSM-IV-TR]; American Psychiatric Association, 2000). Symptom of the Autism is highly heterogeneous and can range from severe impairment to mild delay (Mesibov & Shea, 1996). Autism now affects a significant number of students in schools. It is well documented that the unique learning characteristics of these students differ widely from other learners, requiring teachers to possess

specialized skills (Simpson, 2005a). Despite advancements in instructional practices for students with Autism, little attention has been given to examining the qualities of special and general education teachers who deliver services to these students in complete sessions (Jordan, 2005).

Between 1995 and 2008, the number of American school children receiving special education services for Autism rose from 22,000 to over 140,000 (Fredericks, 2008). The rise in reported numbers of students with Autism in public schools, poor educational outcomes, increased litigation, and an expansion of knowledge of educational practices effective with this population has led to a sense of urgency among educators and parents to ensure students are provided an appropriate education. These data present a challenge to school teachers to become better prepared to serve children with Autism, both instructionally and socially. Additionally, increasing legislative demands placing an emphasis on teacher qualities raise questions about teachers who serve students with Autism. As a result, it has become increasingly necessary to ensure school teachers are adequately prepared and possess requisite knowledge and skills. To meet the needs of the growing number of students with Autism and to take the necessary action to assist them, school teachers must become aware of Autism. Awareness of Autism is the first step in supporting and serving students with Autism. Teachers need to learn about the nature of Autism and about the needs of children with Autism.

School teachers, have the capacity to change practice within the school and to affect the instruction of students with Autism. The knowledge held by the teachers is information that can create change, either by creating grounds for action or by making an individual (or institution) capable of different or more effective action (Drucker, 1989). Because of the increasing popularity of Autism, every public school teacher is likely to serve students with Autism.

However, many teachers lack appropriate awareness, knowledge, and understanding of Autism to meet the needs of these students in the public schools. Little is known about what factors are associated with awareness, knowledge, and understanding of Autism among school teachers (Schwartz & Drager, 2008).

Based on an analysis of the study, little research has evaluated qualities of teachers who serve students with Autism. It is well documented that the learning characteristics of these individuals differ widely from other learners requiring teachers to possess specialized skills (Simpson, 2005b). Research is needed to determine whether teachers possess knowledge of educational practices critical for the improvement of students with Autism, whether they implement these practices into the classroom, as well as training needs of these teachers.

Some determinations have been made to assess the knowledge base of teachers and other educational professionals about Autism. For example, Stone and Rosenbaum (1988) found that teachers held incorrect beliefs about students with Autism, particularly in the area of cognition, when compared to Autism experts. Other studies have shown that speech-language pathologists demonstrated inadequate knowledge of strategies for inclusion (Cascella & Colella, 2004). Furthermore, despite demonstration of accurate knowledge about Autism, medical professionals have been shown to make recommendations changeable with their knowledge (Kennedy, Regehr, Rosenfield, Roberts & Lingard, 2004).

A study comparing special education teachers to general education teachers found pronounced differences between the two groups (Buell, Hallam, Gamel-McCormick & Scheer, 1999). For example, general education teachers expressed more need for inclusion training than special education teachers. Moreover, special education teachers expressed greater confidence in performing inclusion related tasks such as adapting curricula, participating in IEP meetings, and writing behavioral objectives.

**Hendricks (2007)** in his study evaluated special education teachers' knowledge and implementation of educational practices critical for the improvement of students with Autism and determined areas of training needs. A total of 498 special education teachers were surveyed, Participants reported a low to transitional level of knowledge as well as implementation of practices. The most frequently reported was a need for training in social skills development, and the least frequently reported was training in individualization and support strategies. Relationships between the level of knowledge, implementation, and training needs and teachers' occupational characteristics were explored. Plentiful occupational characteristics were found to have a relationship with level of knowledge and implementation, including area of



commendation, educational level, educational setting, number of students with Autism taught, and student learning characteristics.

It is now widely believed that teacher qualities have a significant impact on student achievement (Darling-Hammond & Youngs, 2002). The plan in person in the No Child Left Behind Act of 2001 (NCLB) and the Individuals with Disabilities Improvement Act (IDEA, 2004) recognized the importance of teacher quality, and as a result, set the goal that all students are taught by a "highly qualified teacher" (HQT). In a more recent study conducted by the Center on Personnel Studies in Special Education (COPSSE), Brownell, Ross, Colon and McCallum (2003) analyzed special education teacher preparation programs. They concluded special education teachers require instruction in both subject matter knowledge as well as instructional training.

Recently, a number of studies have evaluated the knowledge, practices, and training needs of professionals who work with individuals with Autism. Cascella & Colella (2004) investigated the knowledge of Autism spectrum disorders among speech language pathologists. Eighty-two speech-language pathologists working in schools in Connecticut were surveyed. Knowledge was assessed by asking questions about behavioral characteristics, communication characteristics, related education and intervention strategies, assessment formats, and inclusion strategies.

Participants reported the most knowledge in behavioral and communication characteristics associated with Autism spectrum disorders, and the least knowledge in education and intervention strategies.

- **Stahmer, Collings and Palinkas (2005)** examined the knowledge and practices of early intervention service providers. Twenty-two early involvement specialists who worked with children with Autism under the age of five participated in focus groups. Providers reported using mostly non-evidence based techniques. Of the 30 interventions listed, only one third were confirmation based. Participants reported wanting to use only those methods shown to be effective, but few had analyzed the literature on the techniques used. All providers reported concerns about adequate training and desired further information on interventions that are effective with children with Autism.

- **Stone and Rosenbaum (1988)** examined teachers' knowledge and beliefs about Autism and found teachers had many misunderstandings about the disorder. Experience with students with Autism ranged from 1-19 years. Teachers held multiple certifications, with emotional disturbance and mental retardation being the most common. Whaley (2002) completed a dissertation surveying special education teachers who work with students with Autism in Tennessee. The knowledge of history and educational programming, the types of teaching methodologies implemented, and the training needs of teachers were evaluated. A total of 292 special education teachers working in 11 school districts in Tennessee completed surveys. On the knowledge portion of the survey, special educators were asked true false questions about etiology and educational programming. In etiology, teachers had a mean score of 73% correct. In educational programming, teachers received a mean score of 79%. However, there were some similar misconceptions. Teachers inappropriately viewed Autism as an emotional disorder, despite evidence that it is neurobiological in nature. Assessment of training needs of special education teachers indicated most (77%) wanted further training in strategies to support students with Autism. Results of this study indicated special education teachers lack an understanding of the research base regarding Autism. Most teachers desired more training in this area. However, teachers may benefit from training that will provide not only information on successful teaching strategies, but also provide information on evaluating research and determining treatment effectiveness.

According to (U.S. Department of Education, 2001), over 20% of children with Autism spend most of their time in a regular education classroom. Given this rise in the mainstreaming of children with Autism, a successful teaching for this population needs for better understanding the general educators' variables affecting it (Swaim & Morgan, 2001). Precisely, there is a shortage of literature that examines general educators' knowledge, self-efficacy, and concerns in teaching students with Autism in comparison to special educators. Additionally, little attention in assessing teacher knowledge of the characteristics of the disorder has been noted (Jennett, Harris & Mesibov, 2003). Direct experience in dealing with students with special needs is a critical factor in general educators' efficacy of teaching such a population and with their ability to include such students in their class (Giangreco, Dennis, Cloniger,

Edelman & Schattman, 1993). Specially, research indicates that general educators who teach children with disabilities do not have the capabilities necessary to meet the needs of these special learners (Campbell- Whatley,

Obiakor & Algozzine, 1995). A sample of 72 educators was assessed regarding knowledge of Autism characteristics, beliefs about etiology, effective teaching practices, and teacher training needs (Helps, Newsom-Davis & Callias, 1999). Findings revealed that teachers in mainstream schools had generally poorer knowledge of Autism and had less training than the special educators group. Teachers of both groups embraced misconceptions about the disorder including the trend not to view children with Autism as having learning difficulties (Helps et al., 1999).

Mavroupoulou and Padeliadu (2000) conducted one of the few studies that examined general educators' (n=35) and special educators'(n=29) general knowledge of the Autism disorder and views of the instructional goals for these children. Both groups of teachers rated several problematic features of Autism (i.e., sleep, eating problems) as the least significant features of Autism. Additionally, a significant number of teachers in both groups felt that psychotherapy is an effective form of treatment for the Autism disorder. In general, special educators in this study

Concluded that more thorough knowledge of Autism and promoted instruction in all major deficit areas like learning disability, communication skills etc....

- **Seagal (2008)** proposed the Autism Inclusion Questionnaire, to assess the constructs of experience, knowledge, attitudes towards inclusion, and classroom practices as they relate to Autism. Results indicated that education professionals ( $N = 47$ ) reported generally positive attitudes; educators demonstrated important misconceptions and lack of knowledge regarding Autism. Further, a significant relationship was found between knowledge of Autism and awareness of potential classroom strategies for inclusion, whereas attitudes and awareness of strategies were unrelated.
- **Schwarber (2006)** also examined teachers' knowledge of symptoms, concerns, and self-efficacy in teaching children with Autism. The sample of 166 preschool general education teachers ( $n=105$ ), special education teachers ( $n=29$ ), and other educational professionals (i.e., occupational therapists, and speech pathologists) attending an in-service from eleven elementary schools were selected from four

school districts in the Midwest. Results indicated that there was confusion regarding Autism knowledge amongst all educators. Special educators had more knowledge, higher self-efficacy, and less concern in teaching children with Autism than general education teachers. In summary, recent research suggests that general educators found themselves unproductively prepared to teach children with disabilities (Sprague & Pennell, 2000). Additionally, general educators receive limited preparation to meet the academic needs of students with disabilities, and few believed that they have sufficient time, skills, training, or resources necessary for successful inclusion. Given the increase in children being diagnosed with Autism and included in regular education classrooms (U.S. Department of Education, 2001) and the link between teacher self-efficacy, knowledge, and effective teaching (Brownell & Pajares, 1999), more research is necessary to determine the relationship between knowledge/skill level and self-efficacy in teaching children with severe disabilities.

## **Conclusion**

The information discussed thus far leads to the following conclusions; school teachers have relatively a lack of knowledge about Autism. This finding support the importance of professional development, training should be provided to the educators in the requirement and needs area of students with autism. Different variables such as teachers' (position, education level, experience, and contact with students with Autism) were found to have a significant direct effect on the level of teachers knowledge about the Autism. School teachers who serve students with Autism in inclusive sittings present with a wide array of characteristics and qualifications. All School teachers, regardless of specific qualifications, should receive training in educational practices needed to effectively serve this group of students. General education teacher programs are deeply in need of more special education classes regarding children with infrequencies as its attention. More research on the general education teachers' skill and knowledge level of teaching the special needs population as well as additional research on the benefits of special education/general education co-teaching of classes would aid in the development of effective mainstreaming practices.

- **Kristina Lopez (2013)** in his study on “Socio-Cultural Perspectives of Latino Children with Autism and their Families” Modification of the Socio cultural Framework for Health Service Disparities.

The Socio-cultural Framework for Health Service Disparities (SCF-HSD) was developed by Alegría, Pescolido, Williams, and Canino's (2011), out of their recognition that previous research on health disparities report stagnant findings with little or no improvement in the understanding and reduction of health disparities. Algeria et al., define health disparities as “racial and ethnic differences in access, health care quality or health care outcomes that are not due to clinical needs or the appropriateness of treatment”. Algeria et al. suggested that disparities are intensified by barriers to access to health care systems, and the low quality and lack of availability of culturally sensitive treatment and service providers. A model of health disparities among racial/ethnic minorities is delineated to explain the multiple interacting factors that contribute to the determination of health disparities.

Service utilization is dependent on the same factors that shape disparities, meaning that patients attend to the quality and content of services and provider interactions in their choice to use a given service. Community perceptions of the health care system also impact patient service utilization (Olafsdottir & Pescosolido, 2009). Alegría et al. assert that culture impacts health and health care among racial/ethnic groups. According to Alegria et al. identifying the unique contribution of cultural characteristics, traditions, values, and beliefs, as well as the role of societal perceptions of cultural groups provides insight about access, quality, and outcomes of health care among racial and ethnic groups.

Alegría et al. propose that racial/ethnic groups have community and treatment system experiences and routines at each stage of managing health and illness problems which energy health disparities. Varying levels of disadvantage and advantage, numerous social structures, and culture affect inequalities in health over the illness career. Furthermore, the points for intervention according to the SCF-HSD include the interaction points between community and treatment. The interaction points are broken down to three levels of analysis, the micro level (individual; provider or patient), meso level (organizational; formal organizations or lay sectors), and the macro level (societal; larger policy or environmental contexts).

Over 90% of the children were male. Mothers averaged 33.17 years of age. 83% of mothers reported their ethnicity as Mexican/Mexican-American/Chicano, followed by 5.6% other Latino, 5.6% Puerto Rican, and 5.6% Latino/non-Latino. 16 module one participants participated in module two. Of the three participants who dropped out, one dropped after two sessions and two others after the first session. Reasons for leaving the study were not provided by the participants. This left the retention rate at 81%. The mean age of the 13 children who completed both the pre and posttests in module two was 6.15. Children averaged 2.62 behavior problems, as measured by the SIB-R. Mothers mean age was 33.62( $SD=6.86$ ) years. 92% percent of the participants were Mexican/Mexican-American/Chicano and 7.7% Puerto Rican. The majority of mothers in both modules were born in Latin America. The average number of years mothers had been in the US was 12.41 ( $SD=4.45$ ) with a range of 4 to 25 years. The majority of mothers did not have a high school diploma, were unemployed, and were either married or living with a partner. Household incomes for most mothers were less than \$20,000 a year.

### **Latino children and families**

Between the 2000 and 2010 census the Latino population grew by 43 percent and encompassed more than half of the total population growth in the United States (U.S. Census, 2010). More than 50 million Latinos reside in the United States, with the Mexican origin population comprising 31.8 million, followed by Puerto Ricans (4.6 million), Cubans (1.8 million), and those of all other Hispanic origin (12.3 million). The median age of Latinos is lower than that of any other racial/ethnic group at 27 years of age. 23.1% of children 17 years of age and younger belong to Latino population.. By the year 2050 Latinos are expected to make up 30% of the US population (Pew Hispanic Center, 2011). The Latino population within all fifty states has increased, with some states experiencing substantial growth such as South Carolina where Latinos grew by 148%. The majority of Latinos continue to reside in California, Texas, and Florida. The population growth among Latinos was met with an increased number of families and children living in poverty. The Pew Hispanic Center reported that Latinos have the highest rates of poverty. Based on the Supplemental Poverty Measure, a new census measure that uses a wider range of factors than the official federal measure to determine poverty status, 28.2% of Latinos

live in poverty (2011). The rate exceeds all other groups and the national poverty line of 16%. Latino children were hardest hit in the wake of the economic decline. Latino children experienced the greatest increase in poverty over the years of the recession, comprising 37.3% of all children living in poverty in the United States. Economic factors much responsible leads to high poverty rates include group expansion, birth rates, limited economic and educational opportunities, immigrant status, and single parent households, (Pew Hispanic Center, 2011). Additionally, the majority of Latino children living in poverty have immigrant parents (4.1 million). Most children across the categories of parental backgrounds were born in the United States.

## **Conclusion**

Latino children with autism and their families encounter inconsistent factors that limit intellectual knowledge about their experiences and limited access to and utilization of intervention. Using the Socio-cultural Framework for Health Service Disparities the disparities are defined as a social injustice to Latino children and families in this chapter. Further, the factors that produce cumulative disadvantage prevent understanding the Latino family experience and limit the development of culturally-informed interventions for Latino children with autism and their families were explored. The SCF-HSD was expanded to include child and parent factors, as well as relevant autism-related outcomes such as family burden. A modified conceptual model that includes variables at the micro and meso levels is provided. The modified model offers several new hypotheses for researchers to explore in an effort to expand the understanding of Latino families raising children with autism, inform the development of culturally-informed policies and care, and reduce disparities. The next two chapters isolate factors from the modified conceptual model and use data to empirically explore their relevancy.

- **Dr. Aadil Bashir, Shabana khurshid (April-2014)**, in his study on “Awareness and Problems of Parents of Children with Autism Spectrum Disorders in Srinagar” concluded Autism has been described as a condition with a greater number of stress than any other disability. Research that has been accomplished is explored and used as a basis to study new directions required to meet the needs of parents coping with the demands. Raising a child with autism is one of the hardest things a parent will ever have to do.

Autism is a disorder that affects children throughout the entire world. It is a neural developmental disorder characterized by impaired and deviant social interaction and communication, in addition to stereotypical behavior and preventive interest.

- Children with autism often have a restrictive range of expression (Cashin, 2005). A study by Hackett 1999 found that families did not initially report concern about the children with autism because they accepted their behavior as a part of their age and did not consider it to be suggestive of any particular disorder and its attributed to their lack of awareness in society. The major findings of the present study concluded that majority of parents suffered due to over expenditure on treatment of child due to which other expenses did not meet and affect overall family.
- **The objectives of the present study are as follows**
- 1) To assess the awareness of parents regarding Autism Spectrum Disorder.
- 2) To study various challenges faced by parents of children with Autism Spectrum Disorder.
- **Sample and Sampling Technique:** The sample of the present study comprised parents of five autistic children who were screened through standardized tool namely ISAA from urban areas of district Srinagar.
- Systematic random sampling technique was used to select the respondents.



### Different dimensions on autism

<b>Problems faced by Parents</b>	
<b>Variables</b>	<b>Percentage</b>
Social stigma	20%
Financial	60%
Lack of Awareness	20%
<b>Things that affect the family most</b>	
Extra-expenses	20%
Social Stigma	20%
Mental stress	40%
Burden of over-caring	20%
<b>Perception of parents regarding attribution of child's disability</b>	
God's will	60%
Past sins done by parents	0%
Lack of medical facilities	20%
Lack of awareness.	20%
<b>Coping Strategies adopted by Parents</b>	
Family Support	40%
Faith on God	40%
Financial Security	20%
<b>Perception of parents regarding the impact of disable child on their life</b>	
Yes	60%
No	40%
<b>Awareness of parents about Autism Spectrum Disorder</b>	
Yes	20%
No	80%
<b>Awareness of Parents about Intervention therapies for children with autism</b>	
Yes	40%
No	60%

Parents have been affected in different ways but majority of them stated that mental stress invites many problems in family as their whole mind and time revolves around the disable child. The life of the parents has entirely changed and usually experience social isolation which shattered their mental and physical wellbeing. Researcher also observed mothers was usually seen most affected by the stress-induced factors that result from raising a child with disability. Some percent of parents expressed that unexpected pressures from society affect their day to day life as their child always become the reason of criticism. Results also indicate that majority of parents were worried about the child as the medication and other treatments did not bring any improvement in his /her condition. It is seen from the results that family support and faith on God bring positive attitude among parents and act as a motivation and coping mechanism while dealing with day to day challenges of disable child. Result also bring out that majority of parents were not aware about the autism disorder however only few percent were exposed about the ASD. Keeping in view the above findings there is a calamitous need to spread awareness among local masses especially parents to get sensitized about the alarming disorder so to come forward and have exposure of different remedial measures which helps to bring holistic changes in children with ASD.

## **I. INTRODUCTION**

It's widely agreed that parenting is the hardest job of all -- and this is especially true for parents of children with autism, who face a different set of challenges. Autism is a developmental disorder that appears in early childhood, usually before age 3.

While cases range from mild to severe, all autism spectrum disorders affect a child's ability to communicate and interact with others. Even though the struggles facing parents of children with autism can seem overwhelming, the good news is that for every challenge, experts say there are solutions to ease the stress and worry that can accompany this very difficult role (Daley, 2002). Various research reports stated that parents of disabled children are particularly vulnerable to stress as high levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children. In addition, both the general psychological literature and specific studies of disabled children show that parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioral and social

development. Although there are many other developmental disorders, autism is unique in several ways.

First, this disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, and blindness. Without a definitive test, the diagnosis of and prognosis for autism is anxious with uncertainty. This uncertainty makes it extremely difficult for parents to accept the child's condition and second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. As a result, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children than parents of children with other physical or learning disabilities or parents with children with other developmental disabilities (Budzienski, 2014). Characteristics that are common among children with autism and contribute to parenting stress include distributed intellectual abilities or isolated skills and persistent problem behavior such as self-stimulatory behaviors. The deficit in emotional expressiveness of autistic children may lower empathy between mother and child, and thus induce greater parental stress. Existing studies of families of children with autism suggest that behavioral, social, and cognitive dimensions of the disorder are associated with stress in parents. It is true, that the more severe the child's symptoms, the greater will be the degree of parental stress. Furthermore, the more the negative characteristics a child has, the more socially isolated the family will be and more the feelings of stigmatization that they will experience (Pathappili, 2011).

**Gray (2003)** conducted a study in found that almost all parents with children with autism have felt stigmatized in public situations for example at the supermarket or a shopping mall), and that parents of younger and/or more severely disabled children felt more stigmatized.

Other important factors associated with parental stress in families of children with autism, include, feelings loss of personal control, absence of spousal support, informal and professional support. Research further suggests that parents of autistic children are likely to encounter increased risks of experiencing persistent feelings of distress

and sorrow. the uncertainty generated by the unpredictability of their child's future quality of life, and stress related to the child's lack of ability to communicate or to his incomprehensible and curious behavior, may hinder the development of adequate parenting practices (Ebata et al). Parents also feel overwhelmed by the challenges of achieving the social inclusion of their child both at school and in the community. Gray 1993 found in a study that many parents have reported positive experiences about rearing a child with autism. They find greater meaning in their own lives, and being delighted with their child's accomplishments , Despite these positive reports substantial research evidences indicates that the parents of children with autism , especially mothers , experience greater amounts of stress and depression than do the parents of children who are developing in typical ways or who have other types of developmental disorder. The first challenge parents of children with ASD face is the diagnosis itself, which can bring heartbreak, anxiety, anger and a feeling that life has been unfair. Another hurdle for parents is the strain having a child with such extensive needs places on the family unit.

According to Autism Society they highlighted that siblings feel overshadowed by the needs of the child with autism, and while some are able to form a close relationship, others may suffer the loss of a typical playmate. But there is certainly hope in this empire. It is important to remember that while having a sibling with autism or any other disability is a challenge to a child, it is not an unbeatable obstacle. Most children handle the challenge effectively, and many of them respond with love, grace, and humor far beyond their years." Many parents of autistic children also report feeling a lack of support.

- **Sauna (2008)**, A study published in the journal Qualitative Health Research in found that a common feeling which is found in majority of families are extreme social isolation and a lack of understanding about the disorder. Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Autism Speaks recommends that parents consult with their child's team -- usually consisting of special education teachers, the occupational therapist, the speech-language pathologist, the behavioral therapist and other professionals who may provide direct services -- to help them create a

constant plan for dealing with challenging behaviors in and out of school. Parents also faced heavy financial demands of having a child with autism.

Keeping in view the above statements and studies it's commanding that families of autistic children need proper guidance and support from the society in order to overcome their problem while dealing with such children. Government and policy makers should formulate and introduce new practices in special schools which are meant for these children only so that it could help them to bring improvement in their day to day life.

- **Muhammad Mahajnah 1,2 , Rajech Sharkia 3,4, Haitham Shalabe1, Ruth Terkel-Dawer 5, Ashraf Akawi 1 and Nathanel Zelnik 2,5 .** “Clinical Characteristics of Autism Spectrum Disorder in Israel - Impact of Ethnic and Social Diversities”.

Despite the increased global frequency and recognition of autistic spectrum disorder (ASD), it is still scarcely reported in the Arab world. Though Israel has a higher prevalence of ASD, a previous national survey of patients diagnosed between 1972-2004, demonstrated that 98% of them were of Jewish ancestry. The disproportional low number of Arab children with ASD in Israel is unclear, but may reflect lower awareness and cultural bias. In the present study we collected clinical and demographic characteristics of 200 children with ASD from Arab and Jewish sectors in Israel that were evaluated in two child development centers. We associated the prevalence and the medical co morbidity of autism between these two ethnics groups. The medical and psychiatric co morbidity profile in these children was similar to the worldwide published studies. In the present study the prevalence of autism in the Arab sector in Israel was similar to that of the Jewish sector. The Arab patients presented with more severe autistic exhibitions and higher occurrence of mental retardation, hereditary members with autism, and consanguinity ( $P<0.05$ ). While in the Jewish sector milder forms (such as Asperger syndrome and PDD-NOS) were more frequent. This inconsistency might be explained by both genetic and cultural factors.

- 🌈 Approximately 4,300 pediatric patients are referred annually to both child development and pediatric neurology centers for assessment of neurodevelopment difficulties.

Out of them 69% are Jews, while the rest (31%) are Arabs. Among them, within the last five years (2008–2013) 200 children were spotted with ASD and were included in the current study. 55% of the Jews male child suspected as a first child relatives with autism.

8.5% of the Arabs male were suspected as a first relatives with autism. 17% of the Arabs female were suspected as a first relatives with autism. Result Contains selected characteristics of the 200 children with ASD and for the each group separately. The male to female ratio of the total sample was 7.3:1. Among Jews this ratio was higher (10.76:1) than among Arabs (4.4:1) ( $P=0.037$ ). The mean age of diagnosed patients was  $37.2 \pm 16.3$  months (range 30.9 to 53.5) with no significant difference between Arabs and Jews. In both communities, most children were diagnosed with ASD before school entry, indicating an increased awareness of autistic disorders at early age. The data showed that there is a significant difference between Arabs and Jews regarding relatives with Autism (17% vs. 8.5%) and consanguinity (21.1% vs. 2.3%), respectively. The course of pregnancy and birth were also investigated and the researcher found that while vaginal delivery was more common in Arab women, caesarian section and vacuum extraction were more commonly among Jewish women. While the prevalence of "classic" autistic disorder was relatively higher among Arab patients, both Asperger's disorder and PDD-NOS were relatively more prevalent in the Jewish patients. The majority of our patients were diagnosed as a primary autism (68.5%) with the others as secondary reversion. Additionally, there was no significant difference between Jewish and Arab patients according to this type of diagnoses. In this study the mean CARS scale was quite high (35.38), with Arab patients getting higher score on the scale than Jewish patients, indicating more severe autistic manifestations in the former group.

Subjects were grouped into two groups according to their society: a Jewish group ( $n=129$ , 65%) and an Arab group ( $n=71$ , 35%).

Total Male Respondents were 88%, among them 91% were Jews, and 81.7% were Arabs.

Total Female Respondents were 12%, among them 8.5% were Jews, 18.5% were Arabs.

30.5% of the Jews female suspected as a first relatives with autism

✚ The prevalence of associated disorders that are found in children with ASD in the present study is . The most common co-morbid disorder is sleep disturbance (40.5%) without difference between Arab and Jewish patients. Interestingly, among Jewish patients the second and third common concurrent disorders were found to be anxiety (36.4%) and behavioral difficulties (19.4%), whereas among Arab patients behavioral difficulties (32.4%) and anxiety (16.9%) were observed as the second and third co-morbid disorders respectively. Furthermore, mental retardation and epilepsy were found to be the fourth and the last concurrent disorders with autism among all patients with significant differences between Jew and Arab patients. Jewish autistic patients have more incidence of epilepsy (9.3% vs. 4.2%) than the Arab autistic patients whereas Arab autistic patients have more incidence of mental retardation (14% vs. 8.5%). Table shows the persons who first raised the possibility of the children having an autistic disorder and selected clinical presentation among our patients. It demonstrates that parents were the first to suspect that their children have autistic disorder (69%) in both Jewish and Arab communities. Among Jewish patients, kindergarten teachers more commonly suspected the autistic disorder before the patient reached a physician, whereas among Arab patients this was not the case. Interestingly, it was found that the first and the second common symptoms of ASD among Jewish patients were delay development in language (35.5%) and communication insufficiencies (25%), whereas among Arab patients communication deficits (35.21%) and language delay (29.75%) were found to be the first and the second common symptoms of ASD, respectively. Additionally, a significant difference was found between both groups regarding communication deficits symptoms. Other clinical symptoms did not show any significant differences between the two groups.