Early detection of autism is key in socializing children before entering the school setting

Martha Elsa Lyon
EARLY DETECTION OF AUTISM IS KEY IN SOCIALIZING CHILDREN
BEFORE ENTERING THE SCHOOL SETTING

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Education:
Special Education

by
Martha Elsa Lyon
December 2006
EARLY DETECTION OF AUTISM IS KEY IN SOCIALIZING CHILDREN
BEFORE ENTERING THE SCHOOL SETTING

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Martha Elsa Lyon
December 2006

Approved by:

Dr. Gary Sherwin, First Reader

Dr. Judith Sylva, Second Reader

9-26-06
ABSTRACT

Even though autism is not diagnosed until children are 3 years of age, new research with the help of advanced technology is opening a world of possibilities regarding early detection of autism in children before age 3. Early detection of autism leads to early intervention, which is crucial for socialization before children enter the school setting. This article describes the importance of early detection of autism for socialization. Parents and special educators need to know how to identify early signs of autism to intervene with socialization methods as soon as possible to take advantage of the brain’s plasticity during early development.

This article will assist in informing parents and educators how to detect early signs of autism as soon as possible and will emphasize the importance of early detection for socialization. This article will also provide effective strategies to start the socialization process during infancy.
ACKNOWLEDGMENTS

First of all I would like to thank April Lyon for her help and undying support. Special thanks to my friends Laura Duarte and Shelia Braggs. Thanks to Dr. Thurston, Professor of Special Education, Dr. Wright and Dr. Sylva for their input.
TABLE OF CONTENTS

ABSTRACT .................................................. iii
ACKNOWLEDGMENTS ................................. iv
TABLE OF CONTENTS ................................. v
LIST OF TABLES ....................................... vii

CHAPTER ONE: INTRODUCTION

Problem Statement ................................ 1
Purpose of the Study ............................. 7
Significance of the Project for
Special Education ............................... 9

CHAPTER TWO: LITERATURE REVIEW

Early Detection ................................. 11
Socialization ................................ 19
Treatments/Interventions .................. 22
Summary ........................................ 36

CHAPTER THREE: METHODS

Introduction ..................................... 41
Study Design .................................... 41
Sampling ......................................... 42
Data Collection and Instruments .......... 43
Procedures ....................................... 44
Protection of Human Subjects .......... 45
CHAPTER FOUR: RESULTS AND FINDINGS

Demographic Characteristics of the Respondents ........................................ 47
Importance of Early Detection of Autism .................................................. 48
Importance of Early Intervention for Socialization ..................................... 49
Interview ........................................................................................................ 51
Summary ......................................................................................................... 58

CHAPTER FIVE: DISCUSSION AND RECOMMENDATIONS

Discussion ...................................................................................................... 59
Limitations ..................................................................................................... 60
Recommendations for Special Education ..................................................... 60
Conclusions .................................................................................................. 62

APPENDIX A: QUESTIONNAIRE ................................................................. 65
APPENDIX B: INFORMED CONSENT ......................................................... 68
APPENDIX C: DEBRIEFING STATEMENT ................................................. 70
REFERENCES ............................................................................................... 72
LIST OF TABLES

Table 1. Developmental Signs of Autism in the First Three Years of Life . . . 6

Table 2. Progress of Social Development, First Three Years .................. 18

Table 3. Demographic Characteristics of Parents Who have Children with Autism ........ 50

Table 4. Closed-ended Questions .................. 50
CHAPTER ONE
INTRODUCTION

Problem Statement

Autism is a developmental neurological disorder affecting numerous regions of the brain impairing thinking, feeling, and social functioning. This disorder also known as Autism Spectrum Disorder (ASD) or Pervasive Developmental Disorder (PDD) is diagnosed by the time children are 2 or 3 years of age (Cowley, 2005). Autism is 4 times more prevalent in boys than girls and it affects 1-to-2 in every 1,000 Americans. Statistics show that autism is growing at a rate of 10-17% per year, and it is estimated that by the next decade 4 million Americans will be affected (U.S. Department of Education; National Institute of Mental Health; Autism Society of America, 2005).

Due to the devastating social impairments derived from autism and the rapid increase in children who are being diagnosed with the disease have forced experts to conduct more research geared towards early detection in order to implement new programs that would educate parents, special educators, and other professionals involved with children
who suffer from autism on the importance of socialization before these children transition to a school setting. With new technology available, early detection of autism seems promising giving researchers the opportunity to design new treatments that would address one of the main and most devastating symptoms of autism, socialization. Several methods presently used to detect autism earlier will be reviewed along with the studies which have established the importance of early socialization and the most effective treatments available today. Some guidelines will also be provided to help parents and special educators select the most appropriate treatment/program targeted to meet the unique needs of the individual child who suffers from autism.

Early detection is the first step towards finding appropriate treatment/intervention since the "cure" still not in sight (Gresham, Beebe-Frankenberger, & MacMilan, 1999). Several researchers have promising theories indicating the possibility of detecting autism in infancy (Freeman, 1997). This gives hope to parents, because the way it is today when autism is detected and diagnosed, in many cases, these children are unapproachable making socialization almost an impossible task. When parents are
not able to reach their children intimately they experience feelings of frustration and helplessness (Trespagner, 1999). By the time these children are finally diagnosed with autism, parents and professionals have to race against time in order to try to socialize them before they enter the school setting. Socialization plays an important role in anybody's life, and a person who is not able to grasp those basic skills that should emerge naturally and automatically for most people who are typically developing, are at a grave risk of becoming outsiders in this society.

Therefore it is of primordial urgency for parents and special educators to be informed on the role that early socialization plays especially on children with autism. Most researchers and lay people agree on the importance of socialization of children with and without disabilities as early as possible. Socialization for children with autism is one of the most challenging of their impairments since typically developing infants follow a developmental sequence of emergence in early social-cognitive skills such as joint attention, communicative gestures, gaze, and point following (Carpenter, Pennington, & Rogers, 2002).

Carpenter, Pennington, and Rogers (2002) concluded that children with autism did not follow the same sequence when
it came to joint attention. Suggesting that if all of these skills are involved in the coordination between a social partner and an object of mutual interest then children with autism do not have what it takes to learn to understand others; therefore they do not know how to socialize automatically (see table 1).

Because autism is viewed as a pervasive developmental disorder (PDD) characterized by the impaired development of social interaction (Gresham, Beebe-Frankenberger, & MacMillan, 1999), many studies have been conducted in an effort to understand and intervene at the time when socialization naturally emerges since socialization is such an important aspect of humanity. Joanne Hendrick (1996) said that “Early childhood is a time that can be rich in social learning; it is a dynamic period characterized by many beginnings but few completely attained learnings in the development of social skills and interactions.” This statement was made regarding typically developing children. It is that much more important when it is applied to children who suffer from autism.

Therefore, many treatments have been reviewed for effectiveness in increasing social skills in children with autism, but many experts believe that it is ultimately up
to the families and professionals to research the best intervention that is better suited for the individual child and his/her unique needs (Dunlap, & Fox, 1999). Some programs that have been effective will be reviewed and limitations will be pointed.

The problem addressed in this study is that autism is not being diagnosed until children are 2-3 years old (Gresham, Frankenberger-Beebe, & McMillan, 1999) by then the lack of social skills which is one of the main impairments these children suffer, has devastated their lives and made them strangers in their own homes, because even people as close to them as their parents/caregivers are not able to reach them. Research shows that delays and impairments in the development of social awareness and social skills can affect a child’s early development, because the first 6 years in a child’s life neural differentiation and cell mylinization are at their best. Therefore, if certain skills such as social skills are not learned during this critical time of neural maturation acquisition of skills such as social could be more difficult and it could result in further alterations in their neural functioning (Jensen, & Sinclair, 2002).
Table 1. Developmental Signs of Autism in the First Three Years of Life

**Signs in Infancy**

<table>
<thead>
<tr>
<th>SOCIAL-EMOTIONAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unresponsive</strong></td>
</tr>
<tr>
<td>. no social smile</td>
</tr>
<tr>
<td>. avoidance of eye contact when held</td>
</tr>
<tr>
<td>. fleeting eye contact at a distance</td>
</tr>
<tr>
<td>. lack of anticipatory response to being picked up</td>
</tr>
<tr>
<td>. seems not to like being held</td>
</tr>
<tr>
<td>. seems content left alone</td>
</tr>
<tr>
<td>. fails visually to follow coming and going of primary caregiver</td>
</tr>
<tr>
<td>. doesn’t play peek-a-boo or patty-cake or wave bye-bye</td>
</tr>
<tr>
<td>. fails to show normal 8-month stranger anxiety</td>
</tr>
</tbody>
</table>

**Fails to form strong personal attachments**

**Second and Third Years**

*moves adult hand like a tool*

*insists on sameness and ritualizes routines*

Zero to Three February 1987
Purpose of the Study

The purpose of this study is to determine the importance of early detection of autism for socialization and at the same time examine new research which suggests that it is possible to detect autism earlier than previously believed and pass along the information to parents as well as special educators on how to identify early signs of autism in order to start the socialization process during infancy and implement the most effective methods for socialization available before these children enter the school setting.

Early detection of autism is believed to be possible thanks to new and more advanced technology which has provided new methods such as the use of eye-tracking devise and Functional Magnetic Resonance Imaging (FMRI) as well as the use of The Temperament and Atypical Behavior Scale (TABS) and The Minnesota Test of Affecting Processing (MN TAP) to identify the deficits in socialization during infancy in children with autism, among others (Bagneto, & Neisworth, 1999; Pennington, & Rogers, 2002; Robel, Ennouri, Piana, Vaivre-Douret, Perier, Flament, & Mouren-Simeoni, 2004).
The eye-tracking devise was used by Klin from Yale to identify the deficits that children with autism show such as identifying emotions and displaying socially inappropriate behaviors (Downs, & Smith, 2004). With help from FMRI it was possible to investigate what goes wrong with the autistic mind. It has been found that children with autism have abnormal brain circuitry almost from birth this keeps them from recognizing faces and such abnormalities impair the development of social skills (Dan, 2004).

The TABS, is a national norm-reference measure of atypical self-regulatory behavior disorders in infancy and early childhood, is currently being used as an early childhood indicator of developmental dysfunction (Bagneto, & Neisworth, 1999); and with the use of the MN TAP is recognized that social and cognitive skills emerge in a consistent order across infants, but it is impaired in children with autism (Carpenter, Pennington, & Rogers, 2002). Once the signs have been detected intensive training must begin. This study suggested that 25 hours per week on teaching children with autism to recognize faces is necessary and they provide evidence indicating
that 1 in 4 children are able to recognize faces normally by the time they enter Kindergarten (Dan, 2004).

A qualitative and quantitative procedure will be used to measure parents' and special educators' responses regarding the importance of early detection of autism for early socialization of children before entering the school setting. Using a convenience sample and data obtained from questionnaires and interviews will allow for analysis of the importance of early detection of autism in order to implement programs for early socialization.

Significance of the Project for Special Education

This proposed study is relevant to special educators and parents of children with autism. By informing parents on how to identify early signs of autism displayed by infants before being diagnosed with autism, they will be able to intervene by implementing strategies on socialization techniques taking advantage of the brain's plasticity during infancy (Trepagneir, 1999). Special educators will be able to assist parents/caregivers by providing information, strategies, and helping them find the most effective program for the individual child.
This study contributes to the significance of special education by providing information on how to identify early signs of autism in order to implement appropriate strategies as early as possible and by examining the effectiveness of early intervention programs. This study has the potential of alerting parents and special educators on the importance of early detection for early intervention and providing information on how to find the most effective program for socialization especially tailored to meet the unique needs of the individual with autism before the child enters the school setting. The hope of this study is to alert parents on how to identify early signs of autism and inform them that with early intervention it is possible to minimize the impairments in social skills displayed by children with autism. Special educators need to inform themselves on how to find the most appropriate programs and/or strategies that parents/caregivers can implement on their own. This study has provided some evidence on the importance of early detection of autism in order to implement effective programs for socialization before the child enters the school setting.
CHAPTER TWO
LITERATURE REVIEW

Early Detection

With some level of understanding on the importance of early detection, in 1990 IDEA implemented the provision of early intervention for children under the age of 3, who suffer from Autism Spectrum Disorder (ASD). New scientific research along with new technology is being applied in an effort not only to find the causes, but also to identify earlier signs of autism during infancy. Dr. Thomas Insel, head of the National Institute of Mental Health said, "If we had a way of screening for autism at birth and then could begin very early to retrain the brain that would really be the ticket." Many researchers are busy at work using their expertise to identify signs of autism as early as possible in order to implement appropriate programs that would improve the trajectory of cognitive and social development (Rebfrom Tecca Landa, 1999).

Different methodologies to conduct research are being used in order to provide evidence of the possibility of detection of autism during infancy which is considered to be the crucial time for children to develop social skills.
With the help of new advanced technology, it is now believed that it could be possible to detect autism during infancy. Some researchers believe that by using Functional Magnetic Resonance Imaging (fMRI) among other devices, they are able to see what goes wrong in the autistic brain (Stone, 2005). Dawsen and Aylward from Washington State University assert that children with autism have abnormal brain circuitry almost from birth and because of those abnormalities children with autism are not able to recognize faces, precursors in the development of social skills (Dan, 2004).

New findings from research conducted at the University of California in San Diego and published in the Journal of the American Medical Association is linking autism to an abnormally rapid brain growth during infancy. They have reported that children with autism have abnormally large brains for their age, but due to the fact that autism is rarely diagnosed in children younger then 2 or 3 years of age, researchers have never known how the situation arises (Dan, 2003). Eric Courchesne examined the early-childhood head measurements from 48 preschoolers who suffer from autism and compared them to those of the national norms. He found that the measurements of the brain from those 48
children with autism had been smaller than average at birth but had grown explosively during infancy (Dan, 2003).

Researchers have come up with well researched data for professionals who rely on evidence of developmental delays as primary criterion for eligibility for early intervention. Bagnato, Neisworth, and John, (1999) claim that it is possible to identify autism earlier by looking at the child’s self-regulation and temperament, because atypical self-regulatory behaviors have been correlated with children who are later diagnosed with recognizable neuro-developmental disabilities (e.g., fragile X, autism, ADHD, cerebral palsy). Self-regulatory dysfunction behaviors include: social disengagement, hypersensitivity, overactivity, inattention, underreactivity (Bagneto, Neisworth, & John, 1999).

Therefore, offering a method for early detection of regulatory disorders through the use of a measurement strategy containing three main attributes: (1) an authentic developmentally-appropriate format for data collection; (2) a standardized, norm-referenced data based on samples of young children with typical and atypical development and (3) a behavioral classification system for "regulatory disorders."
For more than ten years researchers have been working on a nationally norm-referenced measure of atypical self-regulatory behavior in infancy and early childhood and they came up with Temperament and Atypical Behavior Scale (TABS) and Early Childhood Indicators of Developmental Dysfunction. TABS is a developmentally appropriate observation rating system for the early screening, assessment, and classification of significant problems in self-regulatory behavior in young children 11 to 71 months of age. It consists of a 55-item assessment tool and a 15-item screener. The items assess authentic child behavior in natural environments and within the family context. It is written at a 3rd grade level and it is completed by those people who know the children well such as: parents, teachers, and caregivers. This assessment tool organizes atypical self-regulatory behaviors within four factors: detached hypersensitive/active, underreactive, and dysregulated. Opponents argue that there is always a missing factor in most studies; in the case of self-regulatory and temperament behaviors the missing factor is a national normative empirical research (Bagnato, Neisworth, & John, 1999).
However, according to Bagnato, Neisworth, and John (1999) potential benefits outweigh the disagreements within researchers, because with early detection of autism comes eligibility and access to early intervention as well as family support and other services such as: eligibility and access to mental health behavioral support, well-defined goals for individualized intervention planning, sensitive benchmarks for monitoring child progress and intervention, standard measurement for interdisciplinary research on neurobehavioral phenotypes in infancy and early childhood (Bagnato, Neisworth, & John, 1999).

The Centers for Disease Control is currently engaging in a 2.5 million-dollar autism awareness campaign called "Learn the Signs Act Early," the goal of this campaign is to educate health care providers and parents on how to identify early signs (red flags) of autism (Stone, 2005). By recognizing the signs of autism as early as possible support to parents, caregivers, and professionals would be provided not only to help them grow, learn and cope, but also to give children with autism the opportunity to live productive, satisfying, and emotionally connected lives (U.S. Department of Education; National Institute of Mental Health; Autism Society of America, 2005).
Studies are constantly being conducted all around the world exploring different angles that might help recognize the early signs of autism. The National Alliance for Autism Research and The National Institute of Child Health and Human Development at 14 different universities from Harvard to Washington are studying the siblings of children with autism, who have a genetic predisposition for the disorder (Dan, 2003). They are measuring the infants’ visual and verbal skills and their social interaction to find early markers of autism before children turn 1 year old (Dan, 2003).

In McMaster University of Ontario, Zwaigenbaum found that 6-month old infants who are later diagnosed with autism, generally have good eye contact but are often quieter and more passive than their peers (Freeman, 1997). These children may also lag behind in motor development (e.g., sitting up, reaching for objects). By their first birthday they show patterns of extreme reactivity. Others exhibited repetitive behaviors (e.g., rocking and fixation), and were less responsive to playful interactions with others (Freeman, 1997). They also looked at how the typically developing children play games such as peek-a-boo and how their faces light up, as they look at the person
who is playing with them. Typically developing children make sounds and reach for the peek-a-boo blanket. However, children with autism show little facial expression. Children with autism may not look at playmate and it takes a lot of energy from the person playing with them to elicit a reaction (Freeman, 1997).

Ami Klin from The Yale Child Study Center is using eye-tracking technology to find differences in the early socialization skills of children with autism. In her research, she found that when children with autism viewed videos of their caregivers or other babies, they focused more on people’s mouths or on objects placed behind them rather than on people’s eyes as it would be the case with typically developing children (Stone, 2005). Typically developing children start socializing with caregivers within a few weeks of being born. It is a natural process that children with autism do not develop unless it is specifically targeted by caregivers and professionals that is why the urgency to detect autism early as early as possible (Downs & Smith, 2004). (see Table 2).
Table 2. Progress of Social Development, First Three Years

<table>
<thead>
<tr>
<th>Behavior Item</th>
<th>Age Expected (Years, months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responds to smiling and talking</td>
<td>6</td>
</tr>
<tr>
<td>Knows mother</td>
<td>12</td>
</tr>
<tr>
<td>Shows marked interest in father</td>
<td>14</td>
</tr>
<tr>
<td>Is sober with strangers</td>
<td>16</td>
</tr>
<tr>
<td>Withdraws from strangers</td>
<td>32</td>
</tr>
<tr>
<td>Responds to &quot;bye-bye&quot;</td>
<td>40</td>
</tr>
<tr>
<td>Responds to inhibitory words</td>
<td>52</td>
</tr>
<tr>
<td>Plays pat-a-cake</td>
<td>52</td>
</tr>
<tr>
<td>Waves &quot;bye-bye&quot;</td>
<td>52</td>
</tr>
<tr>
<td>Is no longer shy toward strangers</td>
<td>1, 3</td>
</tr>
<tr>
<td>Enjoys imitation of adult activities (smoking etc.)</td>
<td>1, 3</td>
</tr>
<tr>
<td>Is interested in and treats another child like an object</td>
<td>1, 6</td>
</tr>
<tr>
<td>Plays alone</td>
<td>1, 6</td>
</tr>
<tr>
<td>Brings things (slippers, etc. to adult (father)</td>
<td>1, 6</td>
</tr>
<tr>
<td>Shows beginning of concept of private ownership</td>
<td>1, 9</td>
</tr>
<tr>
<td>Wishes to participate in household activities</td>
<td>1, 9</td>
</tr>
<tr>
<td>Has much interest and watches other children</td>
<td>2</td>
</tr>
<tr>
<td>Begins parallel play</td>
<td>2</td>
</tr>
<tr>
<td>Is dependent and passive in relation to adults</td>
<td>2</td>
</tr>
<tr>
<td>Is shy towards strangers</td>
<td>2</td>
</tr>
<tr>
<td>Is not sociable; lacks social interest</td>
<td>2, 3</td>
</tr>
<tr>
<td>Is ritualistic in behavior</td>
<td>2, 6</td>
</tr>
<tr>
<td>Is imperious, domineering</td>
<td>2, 6</td>
</tr>
<tr>
<td>Begins to resist adult influence; wants to be independent</td>
<td>2, 6</td>
</tr>
<tr>
<td>Is self-assertive; difficult to handle</td>
<td>2, 6</td>
</tr>
<tr>
<td>Is in conflict with children of own age</td>
<td>2, 6</td>
</tr>
<tr>
<td>Refuses to share toys; ignores requests</td>
<td>2, 6</td>
</tr>
<tr>
<td>Begins to accept suggestions</td>
<td>3</td>
</tr>
<tr>
<td>Has &quot;we&quot; feeling with mother</td>
<td>3</td>
</tr>
<tr>
<td>Likes to relive babyhood</td>
<td>3</td>
</tr>
<tr>
<td>Is independent of mother at nursery school</td>
<td>3</td>
</tr>
<tr>
<td>Tends to establish social contacts with adults</td>
<td>3</td>
</tr>
<tr>
<td>Show imitative, &quot;me too&quot; tendency</td>
<td>3</td>
</tr>
<tr>
<td>Begins strong friendships with peers associates, with</td>
<td>3, 6</td>
</tr>
<tr>
<td>discrimination against others in group</td>
<td></td>
</tr>
</tbody>
</table>

*as is true for all developmental charts, these ages should be regarded as approximate.

Socialization

Many researchers are hypothesizing on what are the different puzzle pieces necessary in the socialization process that children with autism could be missing, but all agree that it is important for these children to learn to socialize as soon as possible (Dunlap & Fox, 1999). Jensen and Sinclair (2002) state that delays in the development of social awareness and social skills can affect all aspects of a child’s early development, because of a reciprocal social process that plays an important role in early learning. Jensen and Sinclair (2002) believe in an optimal period for socialization. They state that the first 6 years in the life of a child is critical to learn social skills, because neuronal differentiation and cell myelination are at a maximum and in order to be effective in altering brain process, teaching, training must occur in the correct sequence and must be specifically targeted for the core skills (Jensen & Sinclair, 2002). They provide evidence suggesting that if certain skills are not learned during neural maturation, acquisition of certain skills may become more difficult later or would result in long-lasting negative effects. This is the case of early impairment in
the development of social awareness and reciprocity (Jensen, & Sinclair, 2002).

Others researchers have studied babies who are later diagnosed with autism and claim that they show abnormal brain circuitry almost from birth attributing that to their inability to recognize faces and therefore not being able to develop social skills (Robel, Ennouri, Piana, Vaivre-Douret, Perier, Flament, & Mouren-Simeoni, 2004). Research from The University of Washington Autism Center, conducted by Dawsen and Aylward (2004) used functional magnetic resonance imaging (FMRI) to compare brain activity between adolescents and adults with autism and normal adolescents and adults; and they found that the region of the brain called fusiform gyrus became active in healthy but not in people with autism when they viewed human faces (Dawsen & Aylward, 2004).

Another brain-imaging study from the same university was conducted by psychiatrist Dager and his colleagues using a technique called resonance spectroscopy, they examined the size of several regions of the brain and found that children with autism had larger amygdalas and concluded that the larger the amygdala, the slower the child learned social skills (Jensen, & Sinclair, 2002).
Advanced technology and new research are offering better understanding regarding the origin of the different impairments suffered by children with autism and are indicating that it is imperative to educate parents and special educators on the more effective ways to help children with autism overcome or at least cope with the impairment of socialization since social skills is a domain in which children with autism show significant difficulties (Happe, 1994; Wing, 1990). Children with autism do not express emotion and they tend to get overwhelmed by social settings (Hobson, Ouston, & Lee, 1989; Prior & Ozonoff, 1998; Volkmer, Cohen, Bergman, Hooks, & Stevenson, 1989); they also exhibit poor social awareness, low flexibility, and awkwardness, limiting their success when it is time for integration into mainstreaming schools (Dunlap & Fox, 1999). With the new technology available, researchers are confident that soon they will be able to detect autism during early infancy. However, the need still remains for effective programs to increase the social skills in children who have been diagnosed with autism.
Treatments/Interventions

For decades researchers have been creating and designing treatments and different forms of interventions with the hope that children with autism would learn to interact with their peers in an appropriate manner. Some of these approaches have been designed in an effort to provide a way for parents to enjoy a "normal" family life such as the one proposed by Schreibman and Koegel (1975), which included the notion that parents and teachers could be effective therapists for their children who suffer from autism (Schreibman & Koegel, 1975). This approach used behavior modification techniques to teach children with autism how to talk and play with others. Such approach offered five general procedures that applied to all situations: 1. identifying the target behavior, 2. presenting proper instructions, 3. prompting correct response, 4. shaping and chaining behavior, and 5. providing effective consequences. The notion of parents and teachers as effective therapists still stands today (Wolf, Resley, Hewett, & Lovaas; Schreibman, & Koegel, 1975).

Recently, research has taken a slightly different path due to the increase in numbers of children who are being
diagnosed with autism and the level of understanding that new technology has provided. Many studies have reported important gains when intervention/treatment is given early (Lovaas, 1987; McGee, Daly, & Jacobs, 1994; McGee, Morrier, & Daly, 2000; Strain, & Cordisco, 1994). Some methods have shown significant results therefore, they have been considered best practices.

However, as of today no one specific treatment has been established standard in treating all children with autism due the uniqueness of each child’s individual personality. Two movements have emerged recently to monitor the different treatments and methods in the market for treating children with autism. One is the development of practice guidelines which are considered to be the best approach in adopting a particular intervention (Jensen & Sinclair, 2003). This approach involves common practices and critical assessment of practices that are available in the state of California including a list of treatments which lack empirical support according to the California Department of Education, (1997).

Two is the Early Intervention Program (EI) which has developed beneficial recommendations for children with autism in the ages of 0-3 (New York state Department of
This program is based on experimental evidence for intensive behavioral and educational programming. However, it does not offer specific strategies for immediate implementation. Nevertheless, there are other methods which have shown effectiveness among some children with autism in research settings (Dunlap & Fox, 1999). Among the most successful programs which have been well-researched are the treatments that have been based on the principles of the theory of Applied Behavior Analysis (ABA)—that behavior rewarded is more likely to be repeated than behavior ignored (Dunlap, 1999; Heflin, & Simpson, 1998; National Research Council, 2002; Odom, at al., 2003; Rogers, 1998; Stahmer, Collings, Palinkas, 2003). Treatment approaches based on this theory have shown effectiveness in systematically teaching skills and in reducing problematic behaviors (Jensen, & Sinclair, 2003).

Recent studies have provided a new level of understanding regarding socialization for children who suffer from autism because it could be complicated (Dunlap & Fox, 1999). It is important to emphasize that parents who have children with autism need a lot of help as early as possible in order for them to achieve a certain level of
"normalcy" in their lives. They need information on researching the different programs available in an effort to find the most effective approach possible better suited for the individual child (Dunlap & Fox, 1999). There is of course, controversy regarding the different programs available. However, there is also agreement among experts on the importance of social integration, early identification, and intervention (National Research Council, 2001; Rapin, 1997; Rogers, 1996; Strain, Wolery, & Izeman, 1998).

One area of disagreement is on which is the appropriate setting for early intervention, some say that it is the home and others say that it is in inclusion programs (Stahmer & Ingersoll, 2004). Stahmer and Ingersoll, (2004) claim that inclusive early intervention is beneficial for children with autism, even though these programs are rare. They assume that inclusion during the toddler years may increase social and language development just as it happens in preschool (Stahmer & Ingersoll, 2004). Their study shows that at entry of CIS, none of the children engaged in social interactions with their peers. In fact they claim that 40% of those children actively avoided peers by moving away to isolated areas when left to
play on their own and moved themselves from the area when placed purposefully in proximity to their peers. At exit, they claim that no child actively avoided peers that in fact 60% who were engaged in social interactions with peers stayed engaged and 25% could respond to initiations and only 35% of the children involved could actively engage in reciprocal interactions (Stahmer, & Ingersoll, 2004).

Some researchers argue that inclusion is only appropriate for children who are older or higher functioning within the autistic spectrum. They claim that in the case of preschool age children, they may not be "behaviorally ready" to benefit (Strain, McGee, & Kohler, 2001). They also argue that preschool children with autism will not be given the appropriate services and take the risk of not being accepted by their peers (Strain, McGee, & Kohler, 2001). There is no data that supports those claims.

On the other hand there are many areas of agreement. Among those areas are: early intervention, an individualized specialized curriculum, family involvement, systematic instruction, and intensity of engagement (Gresham & MacMillan, 1998). Gresham and MacMillan, (1998) add that early intervention has the potential of being effective if
the following guidelines for investigation are followed: 1). Research investigation should use experimental designs that compares various treatment approaches, 2). Subjects should be randomly assigned to treatment and control conditions, 3). Research studies should use standard treatment protocols in which a wide range of behaviors and skills in laboratories and in naturalistic settings are observed, 4). outside evaluators should be used, 5). Treatment integrity in which the treatment is implemented as intended should be assessed, and 6). Longitudinal research designs should be used to assess immediate, intermediate, and long-term effects of treatment for autism (Gresham, & MacKillan, 1998).

Experts also agree that in order for a practice to be effective it needs to recognize that children with autism follow the same development patterns seen in typically developing children in some ways; even when these developmental patterns may differ in rate, content, or sequence. Among the areas of agreement are some elements of effective programs such as:

   Early intervention

   Individualization of services for children and families
Systematic plan for teaching
Specialized curriculum
Intensity of engagement
Family involvement

In addition, all survey participants agreed that parents must have input and involvement in the design and implementation of their child’s individual program (Hurth, Shaw, Izeman, Whaley, Rogers, 1999; Simpson, 2005). They asserts that effective programs should incorporate a variety of objectively verified practices designed to addressed and support the needs of students as well as professionals and families (Hurth, Shaw, izeman, Whaley, & Rogers, 2005).

Simpson (2005) says that NCLB Act of 2001 is calling for effective methods and offers a list of issues and factors for effective practices to use with students with autism related disorders such what questions to ask when selecting a program/method: 1). What are the anticipated outcomes and are those outcomes in harmony with the child’s needs? 2). What are the potential risks associated with the practice? 3). What are the most effective means of evaluating a method or approach? (based on work of Heflin and Simpson, 1998). a). How will the method be evaluated,
and how is the student progress demonstrated, b). How will the evaluation be carried out and to whom would the results be provided, and c). How frequently will an evaluator of an intervention occur? (Simpson, 2005).

Parent involvement is among the main areas of agreement when it comes to finding an effective intervention program especially now that detection of autism is happening earlier in the life of the child (Trespagner, 1999). Due to this phenomenon, more families are seeking services and have higher expectations for potential outcomes. Parents are seeking help in understanding the effects of autism on their child’s early development (Trespagner, 1999). One area of concern is the social emotional functioning, because children with autism do not respond to social interactions and are aloof to and rejecting of social displays from others. Recent studies are focusing on engagement of children with autism and their parents, because these parents need to provide high levels of structured interaction in order for these children to engage with them (Trespagner, 1999). Therefore, they need to have some strategies in place in order for them to foster social interactions properly (Trespagner, 1999).
Greenspan and colleagues emphasized stepping inside the child's ongoing activity in a way that highlights the adult's presence, and to develop "circles of communication" in which rounds of reciprocal social behavior are established, maintained, and developed (Dunlap, & Fox, 1999). Brown and Murray, (2001) also propose that play is an important instrument for social development (Worfberg, 1999), they explain that because of the core deficits of children with autism such as social interaction, it would be of extreme difficulty for them to engage in play (Brown & Murray, 2001).

Therefore, there is a tremendous need for these children to be engaged in early play interventions starting with assessment of play skills in various settings and with a variety of materials. Early levels of play include establishing of engagement and enticing the child into interaction experiences (floor time) (Lovendahl, 2003). During this stage the goal is to gain engagement and attention to the person they are playing with. This person needs to follow the child's lead and join them treating what the child does as intentional and purposeful for example if the child waves arm give it the meaning of "bye, bye" (Rogers, 1999). Always reinforce behavior to increase
likely hood of it happening again. It is essential for these children to continue to expand the content of interaction to avoid the development of rigid routines (Rogers, 1999).

There are other models and programs worth mentioning which have reported significant outcomes as well. Within the home there are programs such as the Relationship Development Intervention-Parents (RDI) which prepares parents to use everyday events as teachable moments. For example a trip to the grocery store is the perfect opportunity for children with autism to learn to adapt to sensory overload (Bagnato, Neisworth, John, 1999). Schopler, (1994) has been an active proponent that a close collaboration between parents and professionals is essential in the efficacy of any treatment (Jensen, & Sinclair, 2002). With the parents in mind the Denver model uses “sensory social routines” conducted by the parents to establish dyadic routines with the child in an effort to increase engagement, in order to develop reciprocity, and to simplify and scaffold social exchange (Rogers, 1999).

A new field of research on emotional contingency is focusing on the role of imitation in interpersonal interactions and non-verbal communication. This method
emphasizes imitation as a capacity present at birth and how it plays an important role in social development of young children (Rogers, 1999). Therefore, Dawson’s and Greenspan’s approaches show that children learn through modeling and observation. They claim that an important goal for early intervention programs should be to teach children with autism how to imitate (Rogers, 1999). In general programs respondents should engage in teaching practices that are theory based, systematic, data based, be responsive to the child’s current behavior/ongoing monitoring, previous performance to plan instruction, interests, sensory preferences, abilities, and evaluation of teaching interventions (Bagneto, Neisworth, John, 1999). Other guidelines provided by Siegel, (1999) include early intervention approaches and shares factors influencing outcomes in intervention (Siegel, 1999). This study states the success of any program rely largely on following factors: Age of initiation of treatment, treatment intensity, parent involvement, pre-treatment, child characteristics (behavior problems), intellectual functioning, and the language capacity of the child (Siegal, 1999). The purpose of this model is to find a set of pretreatment child characteristics intended to be more
specific for selecting a comprehensive program approach based on a match of individual learning profiles and program features (Siegel, 1999).

Methods such as the Applied Behavior Analysis (ABA) are aimed at increasing functional social skills. The main features of this model include: applied behavior analysis, discrete trials (well-delineated and simple stimuli are repeatedly presented and full motor prompting/chaining methods are used to elicit a specific desired behavior), and it is linked to two specific achievements: 1). acquisition of schema for imitative learning, 2). reception of a diversity of novel stimuli unlikely to be spontaneously sought out. This model uses pairing tangible rewards with social rewards to prepare the child for later learning situations where social rewards alone are presented. This model does not teach skills in developmental sequence and it seems to be designed for children with autism who do not imitate, do not comply, who are not socially motivated, but are repetitive, and who are novelty-averse (Siegel, 1999).

Another model that has been considered among the effective ones for socialization is the relationship model or “floor time.” This Greenspan Floor Time Model
(Lovendahl, 2002) was formulated for intervention for children who met the criteria for Multi-system Developmental Disorders (MSDD), a Pervasive Developmental Disorder (PDD), Not Otherwise Specified (NOS), and like disorders, because it addresses deficits in social reciprocity (Lovendahl, 2002). This model requires that the parent/educator gets down on the floor for 20-30 minutes to interact/play with the child in an effort to capitalize on the emotions of the child by following the child’s interest and motivations and to teach the child how to attend to the adult. This model claims to help the child climb the developmental ladder among many other benefits that come later in the child’s development (Dunlap, & Fox, 1999). Children who are more likely to benefit from this model are those who have a diverse repertoire and are highly motivated by choice. Those who might not benefit are children who have a narrow repertoire, are less novelty seeking, and express low response to auditory stimuli. This model must match the child’s predominately impairing symptom perfectly in order for it to be effective (Siegel, 1999).

Stahmer, and Brooks, (2004) conducted a study in which they used a quasi-experimental design to analyze the
outcomes of 20 young children with autism in an inclusive program for children under the age of 3. Outcomes on standardized assessments and functional outcomes were compared at the beginning and end of the program. They found that most of the children with autism increased substantially in the areas of social and play skills (Stahmer & Brooks, 2004). Other programs have shown significant results as well with inclusion in the preschool years. The Inclusive Program for Toddlers with Autism along with the Toddler Center of the Walden Early Childhood Program have conducted their own studies and report excellent outcomes in language and social skills (McGee, Morrier, & Daly, 1999). Other programs have reported similar outcomes Downs, and Smith, (2004) conducted a study and found that participants who had received intensive behavioral treatment including intensive social skills training in cooperative behavior, level of emotional understanding, and aloof behavior; the group with autism did not differ significantly from typically developing children. Their results indicated that high functioning children with autism can develop cooperative social behavior and even advanced “theory of mind” (the ability to understand that other people have thoughts and feelings).
All the reviewed interventions/treatments have shown effectiveness in the area of socialization (Smith, 2004).

Summary

There are disagreements among researchers regarding the one perfect treatment for children with autism to increase social skills, but one area in which everyone agrees is that the key to socialization is early intervention. Therefore, early detection of autism will provide precious time needed in order for children with autism and their families to acquire some level of "normalcy" in their lives (Trespagnier, 1999). There is a lot of new research that has surfaced, due to new technological advances allowing for researchers to look directly into the brain to see the specific areas responsible for functions in socialization such as the brain circuitry and inability to recognize faces therefore interfering with the development of social skills (Dan, 2004).

There are also many interesting findings on how the brain is wired for socialization. Jensen and Sinclair, (2002), found that the larger the amygdala the slower it is for children to learn social skills and that is the case in
children who suffer from autism (Jensen & Sinclair, 2002). It is known that the critical time for social learning is the early childhood years and therefore delays in the development of social skills will affect many aspects of the child's life (Hendricks, 1996), and socialization is exactly where children with autism show significant difficulties (Happe, 1994; Wing, 1990). It has been stated that the first 6 years of life is an optimal period for socialization because cell myelination is at its maximum state to alter the brain's process by teaching and training targeted core skills such as social skills (Jensen, & Sinclair, 2002).

Many researchers have dedicated many years of their lives in search of answers regarding early detection of autism and now it seems that early detection is possible. Due to all the new research available, IDEA 1990 has implemented the provision of intervention for children under 3 years of age also. The Center for Disease Control has launched a 2.5 million dollar autism awareness campaign, "Learn the Signs act Early" in an effort to intervene as soon as possible (Stone, 2005). With the use of FMRI the possibilities are promising; now researchers have been able to show that a child who has been diagnosed
with autism has abnormal brain circuitry from birth that impairs their ability to recognize faces which interferes with normal social skills development (Bagneto & Neisworth, 1999).

Dr. Insel from the National Institute of Mental Health believes that if autism can be detected early there is a chance that the brain can be retrained (Dan 2004). Another study from the University of California in San Diego, found that children with autism suffered from abnormal brain growth during infancy, but that initially they are born with smaller than average brains (Dan, 2004).

Klin from the Yale Child Center is using eye tracking technology to find differences in early social skills in children with autism and found that children who suffered from autism focused more on other things rather than the eyes of their caregivers (Stone, 2005). The National Alliance for Autism Research and the National Institute of Children Health and Human Development teamed up to look at siblings with genetic disposition and measured infant’s visual, verbal skills, and social interactions before they turned 1 year... Zwaigenbaum from McMaster University of Ontario studied 6 month old infants who were suspected of suffering from autism and found that they had good eye
contact but were quieter and more passive than their peers (Dan, 2003).

Finally Bagneto and Neisworth, (1999) believe that early detection of autism is possible by looking at self-regulation and temperament of the child because atypical self-regulatory behavior has been correlated with later diagnosed neuro-development disabilities (Bagneto, & Neiswoth, 1999).

Many treatments have been reviewed and there are agreements as well as disagreement but many of the most effective treatments have many things in common. The following are areas where experts have always agreed. First, there is no one standard treatment for all children with autism (Schreibman, & Koegel, 1975), but early intervention, family involvement, systematic instruction and intensity of engagement, are variables involved in an effective program (Gresham, & MacMillan, 1998).

It is necessary for parents and professionals to work together in order to find programs that have been properly researched with experimental design across various treatment approaches and Simpson, (2005) offers a list of factors to be considered when looking for the best program: 1). What are the anticipated outcomes and do they
harmonize with the child. 2). What are the potential risks. 3). Effective means of evaluating the program (Simpson, 2005). Another big area of agreement is parent involvement in order to engage the child to foster social interactions such as playing. Play is used as an instrument for social development (Brown, & Murray, 2001). Rogers, (1999), suggests that "floor time" works to gain engagement and attention by having the caregiver and/or the professional get down on the floor to interact with the child (Rogers, 1999). PDI prepares parents to use everyday events as teachable moments (Bagnato, Neisworth, John, 1999). The Denver approach of "sensory social routines," teaches parents how to increase engagement with their child, by using modeling and observation to teach children how to imitate (Rogers, 1999). Many effective programs have been reviewed in an effort to provide useful information that parents/caregivers and special educators can consider when looking for the right program to help children with autism minimize the effects of their impaired social skills.
CHAPTER THREE

METHODS

Introduction

The following presents an overview of the steps involved in obtaining and collecting data for the study on the importance of early detection of autism in order to integrate effective programs to increase social skills in children who have not yet been diagnosed with autism but exhibit signs, before entering the school setting and also for children who have been diagnosed with autism.

Study Design

The study reviewed responses from a small sample of parents and special educators on the importance of early detection of autism for socialization before entering the school setting. The research method is a mixed survey design with open and closed items quantitative and qualitative. This method was appropriate in that the sample of parents and special educators were given the opportunity to express their feelings regarding their experiences with children who suffer from autism and how difficult it is for them to socialize once they have
entered the school setting. The questionnaire that will be presented to the sample of parents/caregivers and special educators will be simple and straightforward to assist in reducing the occurrence of uncertainty in completing the form. This design will also allow for duplication of the research. The limitations of the study were; the small sample size, and the prejudices of the responses given by parents regarding their own children. However, this allowed for a more personal approach when talking face-to-face with the participants during the interviews. The research question is; "On a scale of 1-5, how important do you think early detection of autism is; and which traits exhibited by children with autism are considered more important to minimize before the child enters the school setting?"

Sampling

The data was obtained from a total sample of ten (5) special educators and five (5) parents. Fifteen (15) surveys and one interview allowed for an appropriate amount of analysis for research purposes. The selection was convenient based on the amount of special educators, colleagues, known by the researcher and parents,
acquaintances, who have children diagnosed with autism. The criteria for participation in the study will be parents of children with autism who are currently involved in an early intervention program and special educators who provide those services. Approval to conduct the survey was obtained through the special educators and the parents and through the Institutional Review Board California State University San Bernardino (IRB). The surveys were given person to person and one parent was interviewed.

Data Collection and Instruments

Data collected was comprised of the parents’ and special educators’ opinions on the importance of early detection of autism in order to implement effective programs for socialization before children with autism enter the school setting. In addition questions were asked about their marital status, age, gender, ethnicity, and number of children living in same household under the age of 5.

The independent variable was the importance of early detection and the dependent variable was the importance of early socialization. A survey will be used to collect the data, which is attached (see Appendix A).
This survey was pre-tested on a sample of two individuals to determine the length of time needed for respondent to complete the survey. The strengths of this type of instruments was the clarity of information asked for and the anonymity in how it was obtained. The weakness was in the total amount of completed surveys received and the bias associated with asking personal questions about children to their parents and collecting data in same setting.

Procedures

The data was gathered by distributing the surveys to a small sample of parents/caregivers and special educators in person. Informed consent, the survey, and a debriefing letter, as well as permission to conduct the interview were distributed. The participants were parents of children who have been diagnosed with autism and special educators who have worked in a Moderate to Severe preschool. Data was distributed and collected by Martha Lyon over the summer quarter 2006.
Protection of Human Subjects

The rights and welfare of all participants were protected in the study. Participation was on a voluntary basis, and all individuals who participated marked a letter of informed consent (see Appendix B). Also with the survey, a debriefing statement giving information on who to contact was provided if the participants had any concerns or questions (see Appendix C). No significant risks were apparent in the study. Individual information given by the participants will remain anonymous. The findings of the study was shared with parents and special educators in order to emphasize the importance of early detection of autism and the importance of implementing effective programs that address early socialization methods before children enter the school setting.

Data Analysis

Data analysis was conducted using a variety of univariate statistics (descriptive statistics, frequencies, measures of central tendencies). Bivariate analyses to assess significant associations among the various variables will be used as well. Other analyses were determined later, based on the questionnaire/survey.
Summary

The research focused on the experiences of a sample of parents and special educators on the importance of early detection of autism in order to implement effective programs that increase social skills before children enter the school setting. The study may be informative and helpful to parents and special educators who deal with children who lack social skills and understand the importance of such function in society.

The above steps in the method of obtaining data effectively and adequately allowed for measurement of the importance of early detection of autism for socialization of children who suffer from autism before they start school and replicate the study.
CHAPTER FOUR
RESULTS AND FINDINGS

Demographic Characteristics of the Respondents

Table 3 shows the demographic characteristics of the respondents. There were a total of 10 participants in this study. The age of the parents of children with autism ranged from 32-55 years and the mean age of the respondents are 47 years. Approximately half of the respondents are between the ages of 50-57 and less than 50% are between 32 and 35, and the rest are 40, 47, and 63 years of age.

A majority of the sample of parent participants 95% reported that early detection would have been very helpful, because it would have given them the opportunity to work with their children instead of getting frustrated not knowing what to do. The majority of the sample of special educator participants 97% reported that same. Almost all parents are married except for one who is divorced or separated.

The primary caregivers for these children, nearly all of the respondents, (93%) are female, 4.4% are male and 2.2% are both parents. Half of the participants (50%)
responded having between 1 to 2 children only one under 5 years of age living with them.

Half (50.0%) of the participants reported their ethnicity as White/Caucasian, 22.2% are Black/African American, and 15.6% are Hispanic parents and special educators of children who suffer from autism.

In terms of employment, over sixty percent reported being employed and less than twenty-five percent reported being unemployed.

Importance of Early Detection of Autism

Table 4 provides information on the importance of early detection of autism. Ninety-eight percent of the respondents agreed on the importance of early detection of autism and two-percent did not. In addition, those reporting the importance of early detection have been proactive in getting early intervention for their children and are active participants in their children’s education.

In terms of critical values in this study, a chi-square test (chi-square = 7.6. df = 3, p = .055) was conducted on the importance of early detection of autism. The test results nearly approached a statistical significance. Parents of children who suffer from autism
and special educators who render services to these children showed a special interest in learning about the importance of early detection of autism.

Importance of Early Intervention for Socialization

Table 4 provides information on the importance of early intervention for socialization for children who suffer from autism. Ninety-eight percent of the respondents agreed on the importance of socialization and two-percent did not agreed. In addition, those reporting that socialization was important were special educators and parents who are involved in their children’s education and proactive in the IEP process.
Table 3. Demographic Characteristics of Parents Who have Children with Autism

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (N= 5) Mean= 47</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 20</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>20-30</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>30-40</td>
<td>2</td>
<td>45%</td>
</tr>
<tr>
<td>40-50</td>
<td>2</td>
<td>45%</td>
</tr>
<tr>
<td>Over 50</td>
<td>3</td>
<td>60%</td>
</tr>
<tr>
<td>Gender (N=5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>10%</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>90%</td>
</tr>
</tbody>
</table>

Table 4. Closed-ended Questions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of early detection of autism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>10%</td>
</tr>
<tr>
<td>5</td>
<td>9</td>
<td>90%</td>
</tr>
<tr>
<td>Important skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social skills</td>
<td>5</td>
<td>50%</td>
</tr>
<tr>
<td>Communication skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behaviors</td>
<td>2</td>
<td>20%</td>
</tr>
</tbody>
</table>
The Story of Lilly

This is the story of a middle age Hispanic woman, who has raised her 19-year old daughter who suffers from Rett Syndrome. Rett syndrome (RS) is a unique neurodevelopmental disorder, which shows its effects during infancy or early childhood, often misdiagnosed as autism. Celia is a happy typical housewife, who marries her young love and looks forward to starting a family. Celia soon finds out that her wish has become a reality and has gotten pregnant. This event filled her life with the outmost intoxicating feeling of joy she had ever felt.

Celia immediately begins to prepare a nursery with love and anticipation as she happily thinks of names and wonders with enthusiasm if this child is going to be a boy or a girl. The last few months of her pregnancy seemed to have been an eternity anxiously waiting for the arrival of her first born child. After a few months, a beautiful healthy baby girl makes a triumphant entrance into this world filling many lives with an overwhelming feeling of joy. Celia can’t believe that such a small child can bring so much joy to so many people. Celia enjoys and rejoices
in her daughter’s first smile, hearing her first words, taking her first step, and other milestones associated with typically developing infants. Everything seemed to have been going great for the first 9 months until suddenly and unexpectedly, this perfect child completely changed. Celia became hunted by an awful gut feeling that something was going terribly wrong and she had no idea what or why. Celia being a concern parent began to take her child to different doctors asking them questions and wondering what was happening, because her beautiful little girl was acting weird. At first, her fear was that her baby was going deaf, because she seemed to have stopped responding to her name and the first 10 words that she had acquired had suddenly disappeared and was left with peculiar behaviors instead.

At that point the baby was examined by a specialist and he concluded that deafness was not the issue. Celia noticed that her baby sometimes said one word repeatedly, but after three months it would go away. Celia consulted many doctors and became determined to find answers regarding her baby’s peculiar behaviors.

It wasn’t until Celia’s baby Lilly turned 2½ year of age that she was given the dreaded and feared diagnosis of
“autism.” However, Celia remembers with emotion that one doctor actually said to her that this baby was a puzzle that was very hard to figure out, because she exhibited all the typical behaviors of children with autism, but to a very high degree and then some. According to research, parents sometimes know from the start that their child is very different, but by the time children turn 3 there is very little doubt that something is wrong (Trepagnier, 1999).

When Celia’s baby, Lilly, entered school, Celia mentions with sadness that it was one of the hardest days of her life. Celia says that she cried and could not leave her baby alone with a stranger, because until this point she had been the primary caregiver and she knew all of Lilly’s little peculiarities and felt that she was the only one that could handle it properly.

After leaving Lilly in a classroom with her first teacher, she remembers walking to the front door of the special school with tears rolling down her cheeks and before she could take one step outside the door, she turned around and walked back to the classroom to peek in the door and make sure the her little girl was going to be okay without her. However, and to Celia’s disturbing surprise, she
saw her precious angel tied up to a chair with a towel, Celia says that she could not believe her eyes and the only thing that she could do, at that time, was to run away from that school and to cry until she couldn’t cry any more. When she finally calmed down, she went back to the school and asked to talk to the special education teacher. The teacher (special educator) explained that it was the only way they could find to keep Lilly from taking the other children’s food. She would finish her own food and then proceeded to eat everybody else’s as well (Celia laughs).

This experience helped her understand the importance of collaboration and communication with the special educators. Research shows that early intervention programs are effective in producing large developmental gains. However, these gains are attributed to parent involvement, training, and predictable routines both at school and at the home (Bristol et. al, 1996).

At the school setting, Celia became concerned with Lilly’s social skills, because she tended to isolate herself. Children with autism seemed to have their own agenda and resist or ignore parents’ attempts to engage them. Therefore, social interactions are important because their
quality of life will depend on how society regards them and to what degree it accepts them (Trepagnier, 1999).

Celia explains that routines established in the school setting need to be followed at the home, because these kids give the impression that they want to be left alone, but it is a mistake to allow it. Celia makes sure that Lilly is fully included in everyday activities with the family. For example during eating time Celia makes sure that proper behaviors are modeled. The Dawson’s approach, teaches parents to decrease the amount of directedness and to increase their contingent responding through imitation and mirroring (Rogers, 1999). Celia reports that Lilly truly enjoys being around people now because she laughs a lot and looks for opportunities to be around people.

However, the surprises kept on coming to Celia and when Lilly turned 5, her gross motor skills began to regress to the point where she could not run any more and was experiencing problems with swelling and redness in her feet as well as involuntary movement of the hands. Celia immediately looked for help and went to see a podiatrist thinking that there was something going wrong with Lilly’s feet. More to her surprise the podiatrist took one look at her and said, “This child suffers from Rett Syndrome.”
Right away Celia looked for specialists in her area and found the first one in San Diego, CA, where this diagnosis was confirmed. Nevertheless, Celia went to see another specialist in the L.A. area where she found more confirmation, there was no doubt in her mind, Lilly suffered from Rett Syndrome. However, the formal diagnosis was not given until years later. Celia pauses for a minute and takes a deep breath as if she was re-living that moment, when she could finally look at her opponent right in the face. Celia explains that at that time she felt mixed feelings of relief and fear all at the same time. Only now she could concentrate all of her efforts on helping her daughter with the specific areas of concern related to children who suffer from something specific, Rett Syndrome. Because even though, she read all the literature available regarding Rett Syndrome she says that she went through a period of denial, because typically children with Rett Syndrome eventually suffer from scoliosis (spinal curvature caused by a rotation of spinal vertebrae), she thought to herself, "but, that won’t happen to my daughter," and it did and Lilly had to go through surgery to correct it. She also knew that Lilly could eventually suffer from seizures, but she also thought,
"that won’t happen to her," and it did and Lilly must take medication to minimize the effects of seizure activity.

Celia’s advise to parents is to pursue an early diagnosis as soon as they are assaulted with a gut feeling that something is not right with their child, because she believes that early detection is the key in order to help parents cope with the effects of the disability they may encounter and to provide early intervention to their children. Celia explains that in her case it was helpful to know immediately because it helped her prepare as much as possible for future difficulties that she knew would be coming her way. She says that education puts parents two steps ahead and in a strong position to deal with situations associated with disabilities.

Research advises parents to understand that raising a child without disabilities requires courage, patience, and perseverance. A child with autism requires these qualities to a higher degree and for much longer time, sometimes the child’s whole life (Trepagnier, 1999).

Lilly is now 19 year of age and with medication her seizures are under control. She is a happy young lady, who enjoys being around people and loves the attention she gets from friends and family members. Celia is involved in her
community providing support to parents who have children with disabilities and helping special educators understand parents’ needs.

Summary

The overall results of the study found that the primary caregiver respondents from this sample were female, between the ages of 32 to 50 and older, with between one to two children in their care. Nearly half were of Hispanic ethnicity in overall 3 of 5. Most of the special educators were of White ethnicity in overall 4 of 5. There was a significant association between responses from parents and special educators on the importance of early detection of autism, but an overwhelming association between responses from parents and special educators on the importance of communication skills.
CHAPTER FIVE
DISCUSSION AND RECOMMENDATIONS

Discussion

Upon approval from The Institutional Review Board (IRB) to conduct this study, results of this project revealed that less than half of the sample of parents who have children suffering from autism are Hispanic and the majority of the sample of special educators are White/Caucasian. Many of the parents in the sample, as well as the special educators are married. Ninety percent express the importance of early detection of autism for early intervention for increasing communication skills.

Parents are 32 years of age and over, married, and whose ethnicity is Hispanic agreed that early detection of autism is important for early intervention for increasing communication skills and special educators whose ethnicity is White/Caucasian 35 years of age and over, married also believe that early detection is important for intervention in order to increase communication skills.

This study is consistent in that there are parents from different ethnicities whose children suffer from
autism and more special educators who are White/Caucasian ethnicity.

Limitations

A number of limitations of this project should be acknowledged. First of all, the number of participants was low, and a small sample size would significantly compromise the generalization of the findings, and it is plausible that using a larger sample may have resulted in a different outcome. Second, all participants were chosen from one area. Third, the interview with a parent/caregiver allows for biases in response when asking parents about their own children's behavior. Therefore, the results cannot be generalized to a population beyond this sample. Despite these shortcomings, it is hoped that the findings are informative to parents of children with autism and special educators who are involved in these children's socialization process and to propose new research on the subject.

Recommendations for Special Education

The results of the study indicated that the majority of respondents from the sample were aware of the importance of early detection of autism for intervention. Parents
will be more informed on the importance of early detection of autism in order to intervene with effective programs that address socialization, which is a precursor to communication. Special educators will know what to look for when searching for new effective methods to increase social skills in children with autism.

Special education practice dictates that special educators examine different programs to fit the individual needs of children who suffer from autism as well as to inform parents of the different strategies necessary for socialization that they can continue to implement at home in order to later increase communication skills, because without socialization, communication will not occur. Taking a closer look at new information which indicates that it is possible to detect autism during infancy for parents who do not know what to look for and therefore not being able to intervene when the child's brain is still trainable and implement strategies that will allow for these children to learn to socialize so when they get to the school setting that is one less battle they would have to fight and they can go straight to increasing their communication skills.
The study lacked a large enough volume of participants to provide adequate sampling of parents and special educators from different parts of the region and from different backgrounds. Perhaps if the questions would have been asked to people close to the child but not to the parent or main caregiver the answers would have been more objective and the tremendous amount of room for biases would have been eliminated.

The research indicated the importance of more research in order to share new information with parents and special educators on detecting early signs of autism during infancy in order to implement effective programs designed especially to increase social skill in children who suffer from autism. Parents need to learn to identify the early signs of autism early enough and need to know what to do as well. Special educators need to be aware of the different effective programs in place that have been found successful in increasing social skills in children who suffer from autism.

Conclusions

The conclusions drawn from this project is suggestive of the importance of distributing new information out to
parents and special educators on the new research providing guidelines on early signs of autism and on strategies that can be implemented from the beginning in order to comply with new IDEA mandate regarding special services to children who might be at risk. However, this study may have underrepresented parents and caregivers who have never heard of autism and know that something is wrong with their child but have no way of pursuing early detection and would have to wait until their child enters the school setting to find out that the child’s social skills would keep them out of mainstream classrooms.

Greater attention should be given to parents whose children are falling behind, but is still too early for them to be diagnosed with autism. They should be given guidelines on milestones that infants should follow to assure a healthy development especially in early socialization. Adequate training for special educators on the newer programs that have been shown successful results in socializing children with autism as early as possible should be provided; and such information acquired from the training should be shared with parents. In essence, a closer look at providing more information and training to new parents and special educators on early signs of autism
and on effective programs for socialization before these children enter the school setting. Finally greater communication should take place between parents and professionals in order for parents to receive the latest information on program and services available to help them provide a healthy development for their children and to bring to their attention that socialization is a precursor to communication.
APPENDIX A

QUESTIONNAIRE
Importance of Early Detection of Autism for Socialization Questionnaire

Circle one:

1. On a scale of 1-5 (5 being most important), how important do you think early detection of autism is?  
   1  2  3  4  5

   Why?

2. Which of the following skills do you consider more important?

3. 
   1. Communication skills
   2. Social skills
   3. Behaviors (inappropriate, repetitive, aggressive, etc.)
   4. Other

   Why?

Parents Only

4. Do you have strategies to help your child increase social skills?
   1. Yes  2. No

   If yes, what?

Educators Only

5. Do you use special strategies to increase social skills in children with autism?
   1. Yes  2. No

   If yes, list:
Demographics

6. What is your marital status?
   1. Never Married
   2. Married
   3. Other

7. What is your age? __________

8. What is your gender?
   1. Male 2. Female

9. What is your ethnicity?
   1. American Indian or Alaskan Native
   2. Asian or Pacific Islander
   3. Hispanic
   4. Black [African American]
   5. White

10. Are you employed?
    1. Yes 2. No

11. Are you the main caregiver?
    1. Yes 2. No

12. How many children living in the house? __________

13. How many under the age of five? __________

   1. Married
   2. Single
   3. Divorced/Separated
   4. Widowed
   5. Co-habitation
APPENDIX B

INFORMED CONSENT
INFORMED CONSENT

My name is Martha Lyon. I am a second year student in the Masters of Special Education Program at California State University, San Bernardino. I am conducting a survey regarding the importance of early detection of autism for socialization. Participation in this study is totally voluntary and should you choose to participate, you will remain completely anonymous, as no identifying information will be obtained.

Whether you participate or not will not affect you in any way. The results obtained from this study will be presented as a final research project for the Masters of Special Education Program at California State University, San Bernardino. These results will be available to you at the University in the Pfau Library after June, 2006.

The Institutional Review Board (IRB) at California State University, San Bernardino (CSUSB) has approved this project. No significant risks are apparent in this study. I am under the supervision of Dr. Sherwin in the completion of this project. Dr. Sherwin may be reached at the California State University, San Bernardino, Special Education Department, (909) 537-7407.

This survey will take approximately ten (10) minutes to complete. Upon completion, hand the survey to me. I thank you for your participation in this study.

My check mark below indicates that I have been informed of the nature of this study and voluntarily agree to participate. I am at least 18 years of age.

___________ Mark ______________ Date
DEBRIEFING STATEMENT

The study in which you just participated was designed to answer the question, "How important is early detection of autism for socialization."

The results of this study will be available after June, 2006 and you may obtain results from either my advisor Dr. Sherwin, or myself, Martha Lyon Special Education Student, via the Pfau Library, University of San Bernardino, California, (909) 537-7407.

If the study made you feel uncomfortable, or if you have any questions or concerns regarding this study, please contact my Advisor. Thank you for participating in this survey.
REFERENCES


