CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

Autism: A Handbook for Parents

A graduate project in partial fulfillment of the requirements

For the degree of Master of Science in Counseling,

Marriage and Family Therapy

By

Rebecca Gordon

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The project of Rebecca Gordon is approved by:

_____ _____

Cecile G. Schwedes, M.A. Date

_____ _____

Kevin Ham, M.S., MFT Date

_____ _____

Stan Charnofsky, Ph.D., Chair Date

Cal State University, Northridge

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Dedication

I would like to dedicate this to my friend Tobey Ramirez and her son Daniel Ramirez, who have overcome the struggles and challenges of autism. I would also like to dedicate this project to all the families who have children, friends and love ones who are currently dealing with the challenges of autism.

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Abstract

AUTISM: A HANDBOOK FOR PARENTS

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Parents of children with autism often find themselves feeling frustrated and confused, when trying to understand their child's diagnosis, finding the best means of helping their child and themselves. This project is designed to help ease the minds of parents to better understand autism whether they are questioning if their child has an autistic disorder or have a child who has been diagnosed with an autism. This project will provide information including defining autism, diagnostic criteria, treatment options, and resources for autism.

CHAPTER I

Introduction

Introduction

Autism has increased dramatically within the past years. More children are being diagnosed each year due to increased awareness and diagnosis that have been made. Many people in our society may have heard the word autism or know a friend or family that is diagnosed with having autism. Most people have knowledge or some understanding about autism, but they don't know the history of autism.

History of Autism

Paul Eugene

The history of autism begins in the early 1900s. According to the American Psychological Association the term autism was first coined by Swiss psychiatrist, Paul Eugene Bleuler, in the 1911 issue of the American Journal of Insanity. The word autism was used to refer to a form of adult schizophrenia. He also coined the term "schizophrenia" to describe a state of dissociation. He believed there was a correlation between autism and schizophrenia since schizophrenics lacked social skills with others, and were more absorbed in themselves.

Leo Kanner

In 1943 Dr. Leo Kanner, an Austrian-American psychiatrist at John Hopkins Hospital, specialized in child psychology., He was the first to mention autism as a disorder, which he explains in his paper, Austistic Disturbances of Affective Contact." In his paper discuss his observations of eleven children. They consist of eight boys and three girls, which he observes between 1938 and 1943. In his observation he noticed that these children started to withdraw from being in contact with others and being obsessed with sameness as early as the first two

years of their life. He created the term “early infantile autism” to describe this condition, which he wrote about in the journal “The Nervous Child.” He was the first to recognize autism as unique and separate from other childhood conditions. In a 1949, paper he created the term “Refrigerator Mothers.” The idea of Refrigerator Mothers was that their children had autism because of the mother’s frigidity. They were supposedly "cold" to their child and didn't interact or play with them and didn't cuddle them. In a 1960 interview for Time magazine, he made a comment that the parents defrost themselves long enough to create a child, which is a very harsh statement.

Hans Asperger

A year later, in 1944 Hans Asperger, a Viennese child psychologist, of the Vienna Hospital, published the first definition of Asperger’s Syndrome in his paper “Autistic Psychopathy.” He studied four children in his practice. He identified a pattern of behavior and abilities which he called “autistic psychopathy,” meaning autism (self) and psychopathy (personality disease). Asperger’s Syndrome is a high functioning form of autism.

Bruno Bettelheim

In the 1950s, Bruno Bettelheim, child development specialist, who tend to spent most of his career at the University of Chicago's Orthogenic School, which is an institution for "disturbed" children, including autistics as well as "schizophrenic" and others. Eventhough, Kanner coined the term “refrigerator mother” theory, Bruno contributed in the widespread acceptance of his theory by a series of articles in the 1950s and the 1960s. He was also a great self-promoter, and often cited in the media. He was very influenced by Sigmund Feud psychoanalytical theories. He was most prominent between the 1940's and the 1970's. Bruno believed the idea of the refrigerator mother and likened these parents to guards in a Nazi

concentration camp. It is believed that he compared the prisoners' behaviors to that of children with autism. He felt that autism was a psychological disturbance that has risen from frigid and detachment from their mothers. He truly felt that autism disorder was due to women failing to emotionally support their children and leaving them deprived of skills to socialize and communication skills. His most popular therapy for helping children with autism was to remove the child from their mother.

Many mothers whose children were autistic suffered from blame and guilt throughout the 1950's and beyond due to Dr. Bettelheim's theory of Refrigerator Moms. His theory was that autism was the product of mothers who were cold, distant and rejecting, thus deprived of the chance to "bond properly." Dr. Bettelheim's theory was accepted by the medical institutions and went largely uncontested in the mid-1960's, but its effects have lingered into the 21st century. Many of the articles and books published in that era blamed autism on a lack of maternal affection. The flaw in Dr. Bettelheim theory is that some of these mothers had successfully raised their other children, but his theory at that time was assumed to be correct.

Bernard Rimland

In 1946, Dr. Bernard Rimland, a father of a child diagnosed with autism at age two, a psychologist, and autism researcher, the founder of Autism Society of America and Autism Research Institute wrote a book "Infantile Autism: The Syndrome and Its Implications for a Neural Theory Behavior." He is responsible for discrediting the "Refrigerator Mom" theory of autism. Writing this book allowed him to dispute the theories of Leo Kanner and Bruno Bettelheim. He was able to at a stand for the basis of autism, release parents from the guilt that was associated with having a child with autism, and pointing research in the course in should have taken. Dr. Rimland brought hope to thousands of children with autism and their parents.

He worked hard at changing the myth that autism was an emotional disorder caused by "refrigerator mothers" and bringing parents together as self advocates. By the late 1970's no one accepted the theories of "refrigerator moms."

History of Autism in the DSM: DSM: I to DSM: V

DSM

In 1952 the DSM was published. Although autism was seen as a unique and separate from other childhood conditions in 1943, it was still not included in the DSM. Children who were showing signs of autistic behavior were still being diagnosed as having childhood schizophrenia. At that time the DSM only contained 66 disorders with a short list of symptoms for each.

DSM - II

In 1968 the second edition of Diagnostic and Statistics Manuel of Mental Health Disorders (DSM- III) was released. The DSM- II contained over 100 disorders. The DSM-II stated that "the condition may be manifested by autistic, atypical and withdrawn behavior." Children who demonstrated these types of behaviors were diagnosed as schizophrenic, childhood type.

DSM- III

In 1980, the Diagnostic and Statistics Manual of Mental Disorders, Third Edition Revised (DSM-III) was released and autism was a finally known as a separate category with specific criteria. There was only one term that they used at that time and it was known as infantile autism. There were six characteristics and each of them had six symptoms that need to be present for a child to be diagnosed with infantile autism categories. The term infantile was changed due to some controversy of the description. In 1987 the category was changed to autistic disorder.

DSM - IV

In 1994, the Diagnostic and Statistics Manual of Mental Disorders, Fourth Edition (DSM-IV) was released. The American Psychiatric Association added pervasive developmental disorders as a category and also various subtypes. The DSM-IV has a list of sixteen different symptoms used to describe autistic disorder and the patient must show signs of six of the sixteen in order to receive a diagnosis. In addition to autistic disorder, a diagnosis can be made under the categories of Apserger's Disorder, Rett's Disorder, Child Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

DSM - V

In 2010, The American Psychiatric Association released draft revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The DSM-V is expected to affect how autism and related disorders are diagnosed. In the DSM-V, the diagnostic category will be changed to Autism Spectrum Disorders. Asperger Syndrome, Childhood Disintegrative and PDD-NOS will be under the Diagnosis of Autism Spectrum Disorders. Rett's Disorder would be removed from the DSM completely, which would also mean that it would not be included as an autism spectrum. The official fifth revision of the DSM is expected to be published in May 2013.

Statement of Need

The greatest joy for a couple is becoming parents. Thinking about who the child looks likes, being able to hold him or her in their arms, watching him or her smile and coo. The one thing that every parent wants is for his or her child to be healthy and develop normally as he or she gets older. When parents notice that their child is not developing the same as other children their excitement turns into concern. For parents who question or have a child with a disability it can be one of the most confusing, frustrating and stressful times in their lives. They are left with a lot of questions that they don't know the answers to. Parents of children with autism are coping with high levels of stress and confusion about their child's diagnosis. Parents need to know where they can find support that can help them. There are many interventions, treatment and support groups that can assist their children and their family as they get a clearer understanding of autism.

Purpose for the Project

The purpose of this project is to provide parents with clear and concise information defining autism, diagnostic criteria, interventions, and support for parents. This project also explores symptoms, early signs, importance of early intervention, behavior modification, strategies to help family members cope with stress, and become aware of resources and organizations available for support. It is also to help parents better understand the developmental disorder of autism and encourage them to seek more information.

Definition of Terms

Applied Behavioral Analysis: is one of the most widely used treatments for autism and it is based on the theories of behaviorist.

Autism Spectrum Disorder: are a set of disability groups that are identified under the heading of Pervasive Developmental Disorders (PDD).

Co- morbidity: the presence of one or more disorders (or diseases) in addition to a primary disease or disorder

Coping: refers to the thoughts and actions we use to deal with stress

Developmental disabilities: are a group of conditions due to an impairment in physical, learning, language, or behavior areas.

Discrete Trial Training: is a short interactive sequence used to teach a new target behavior

DSM-IV: The official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association.

Diagnostic and Statistical Manual of Mental Disorders (DSM): is the standard classification of mental disorders used by mental health professionals in the United States and contains a listing of diagnostic criteria for every psychiatric disorder recognized by the U.S. healthcare system.

Early Intervention: Services that are provide support to young children from birth to three years old that have or are at risk for developmental disabilities or delays and their families.

Echolalia: Is the immediate or delayed echoing or repetition of whole, expressions or phrases

Pervasive Developmental Disorders: is an umbrella term for a wide spectrum of disorders referred to as Autism or Autism Spectrum Disorders (ASD).

Picture Exchange Communication System: teaches children to exchange symbolic pictures as a way to communicate.

Pervasive Developmental Disorders (PDD): is a behavioral disorder of speech, communication, social interaction, and repetitive type compulsive behaviors and includes Autistic Disorder (autism), Rett's Disorder Child Disintergrative Disorder, Asperger's Disorder and Pervasive Delevopmental Disorder Not Otherwise Specified (PDDNOS).

Prevalence: the number of cases of a specific disease present in a given population at a certain time.

Restricted behavior: is limited in focus, interest, or activity, such as preoccupation with a single television program, toy, or game.

Ritualistic behavior: involves an unvarying pattern of daily activities, such as an unchanging menu or a dressing ritual.

Self-injury: includes movements that injure or can injure the person, such as eye poking, self-pinching, self- scratching, hand biting, hair pulling and head banging.

Social Stories: are stories that are written or pictorial scripted scenarios to support the child with autism that best retain information visually.

Stereotypy: is repetitive or ritualistic movement, posture, or utterance, such as hand flapping, making sounds, head rolling, or body rocking. It is also known as stimming.

Stim: a form of self-stimulation or perseveration, examples are rocking, spinning, or humming

Stress: a state of mental tension and worry caused by problems in your life; something you feel when you have to handle more than you are used to.

Support: to carry, hold up or bear the weight of someone, to provide comfort or encouragement

Tantrum: acting out, this may be accompanied by biting, scratching or other aggressive acts towards one's self or others.

Treatment: a type of therapy or intervention that is used to remedy a health problem.

Organization of Project

Chapter two examines the literature on the impact autism has on the family. The issues that were researched are impact of autism on the parents, siblings and grandparents, coping with stress, prevalence of autism and support for families. Chapter three will discuss the development of the handbook, the targeted population, and an outline of the handbook. Chapter four, which is presents a summary and conclusion. In the Appendix is a handbook for the parents of children diagnosed with autism.

Chapter II

Literature Review

Introduction

Although autism may seem like a new diagnosis, some of the earliest published descriptions of behaviors that resemble autism back to the eighteenth century.

In 1911, a Swiss psychiatrist, Eugene Bleuler coined the autismus, which in English translation is autism. He derived this word from the Greek word autos, which means self and he used it as to refer to autistic withdrawal of his patient. In those days, Autism was a term used to refer to those suffering from a variation of schizophrenia.

In 1943, Leo Kanner first characterized autism, a neurodevelopment disorder, as individual with odd disturbing language, poor human connected, and repetitive or disturbed behavior (Kanner, 1943). Kanner believed that autism was a type of social disability, present at birth, with biological original. Dr. Kanner's definition of autism was referred to as early infantile autism or childhood autism

At the same time as Kanner findings, Hans Asperger made similar discoveries, though all his patient's were verbal (Wobus, 2006). The name Asperger's Sydrome has been used to described high-functioning individuals with typically developing verbal capabilities.

After the diagnosis of autism was the observation that very few children with autism had warmhearted parents (Wobus, 2006). This observation led to the assumption that one cause of autism might be the lack of parental nurturing. Children were removed from their parents for recovery. In the 1960s Bruno Bettelheim, a child psychiatrist, wrote "The Empty Fortress." According to his theory, the cause of autism was believed to be due to a mother's unconscious rejection of her child. His theory was that autism was the product of mothers who were cold,

distant and rejecting, which deprived the children of the chance to "bond properly." Although Kanner coined the term "refrigerator mother" theory, Bruno facilitated its widespread acceptance of the theory by the public.

Defining Autism

Autism is a neurological developmental disorder that impacts children and their communication and social functioning. In 2007 CDC'S autism spectrum disorder and Development Disabilities Monitoring (ADDM) Network released data that found that 1 in 150 that children in multiple areas of the United States that had an a autism spectrum disorder. According to Center to Disease Control and Prevention (CDC, 2012) recent statistics indicate that childhood autism is diagnosed among approximately 1 out of 88 children in the United States. Autism is also the most commonly diagnosed developmental disabilities in the U.S. According to Morrier, Hess, and Heflin (2008) autism is more common in boys than in girls with the ratio of four to one. The CDC also states that ASDs are five times more common among boys (1in 54) than girls (1 in 250).

ASD included in the group of disorders known as pervasive developmental disorders (PDD). PDD is an umbrella term that is used to explain the range of symptoms that are considered developmental. This group includes Asperger's syndrome, Autistic disorder (also called "classic" autism), Rett's syndrome, Pervasive Developmental Disorder Not Otherwise Specified and Childhood Disintegrative Disorder.

Children with autism are typically considered to be more on the chronic end of the autism spectrum and the symptoms that impact their functioning in a wide range of ways. Jensen and Spannagel (2011) reported that the symptoms of autism are generally more visible and require the most intensive interventions. Autism is recognized more by society than other

developmental disorders due to the increase of awareness and education about this disorder. The rate of children that have been diagnosed with autism has grown rapidly over the last five years and it is still growing (Volkmar & Pauls, 2003).

Impact on Families

Parents

Many parents raising a child with autism have reported extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, and guarding their child from danger (Randall & Parker, 1999). There are approximately two thirds of mothers whose children have autism suffer from depression (Bitskita & Sharpley). Many parents have high levels of emotional distress which include depression, anxiety and anger and mothers feel this more than fathers (Gray, 1994). In a study by Kohler (1999), it was found that incredible demands were placed, on a family with a child who had autism, and the stress, associated with these demands. It was found in this study that parents did much of the transporting, paperwork and filing, and attendance at meetings for their child. Most parents discussed the tremendous amount of paperwork involved in receiving services, as was also found in a study by Schall (2000) who noted that families discussed an overwhelming number of visits to doctors, psychologists, hospitals, and therapies. The mothers are more distressed than the fathers because most mothers are the primary caregiver, and have more exposure to negative reactions and looks from outsiders.

According to Dumas, Wolf, Fisman, & Culligan (1991), that families with children with autism have higher levels of stress when compared to families with children with Down's syndrome, behavior disorders, and children with normal development. Gray (1994) also found that parents of children with autism experience high levels of emotional stress, anxiety,

fear and guilt. Gray (1994) confirmed that parents of children with autism are usually the first to recognize the symptoms, and, subsequently, have difficulty in convincing reluctant grandparents and medical personnel of the problem, through interviews with 35 parents of children with autism.

Mothers and fathers share parenting roles, but mothers typically assume a larger part of the responsibility of meeting the needs of the child with ASD (Gray, 2003). Most of the research on stress levels of parents of individuals with ASD has been conducted with mothers (Tomanik, Harris, & Hawkins, 2004). Researchers have found that mothers of individuals with ASD reported more stress, depression, and anxiety than fathers (Hastings, 2003b; Herring et al., 2006). In addition, mothers of individuals with ASD reported more stress than mothers of individuals with DS (Pisula, 2007) and mothers of typically developing children (Yamada et al., 2007). Tomanik et al. (2004) reported that mothers of children with ASD reported the greatest stress when their children were more irritable, socially withdrawn, hyperactive/noncompliant, unable to take care of themselves, and unable to communicate or interact with others.

Researchers found that the impact on fathers of having a child with disabilities is mixed. Some researchers have found favorable outcomes for fathers, whereas others have reported that fathers and mothers experience similar outcomes although their stressors emanate from different sources (Hastings, Kovshoff, Ward, et al., 2005). Gray (2003) investigated gender differences in parents of children with AS and found that fathers reported that their child's condition did not have a significant effect on them personally, whereas mothers claimed that their child's AS severely affected their emotional well-being. There is limited research on the stress levels of fathers who have children with ASD. Most researchers (Herring et al., 2006; Little, 2002) have reported that fathers of individuals with ASD experience less stress, depression, and anxiety than

mothers. Paternal stress was not associated with the child's challenging behavior (Hastings, 2003b; Hastings, Kovshoff, Ward, et al., 2005), but was found to be associated with a partner's depression (Hastings, Kovshoff, Ward, et al., 2005). Sanders and Morgan (1997) identified several factors related to stress perceived by fathers of children with ASD, including actual physical care of the child. They reported that fathers of children with ASD experience more stress as a result of time spent caring for the child and the behavioral characteristics of autism that might make this responsibility difficult.

Couples

Many others reported stress placed on the marriage. Dumas et al., (1991) found stress to be higher among parents of children with autism; than parents of a child without autism. Parents raising a child with autism can face marital challenges. The prevalence of divorce is higher for parents who have a child with autism (Hartley et al., 2010). Spouses are too busy with the activities related to their child's needs to seek out any time for each other. In order for parents to take some time for each other they would probably need to find a babysitter. Finding a baby sitter can be a challenge because they would need to find someone who can cope with their child’s needs. Parents of children with autism are subject to more from stress than parents who have children with other special needs and parents of typically developing children (Lecavalier, Leone, & Wiltz, 2006). According to Osborne and Reed (2009), there is a connection between the severity of behavior of a child with autism and the presence of increased parental stress.

Siblings

Brothers and sisters interaction with one another provides them with opportunity to experience sharing, companionship, rivalry, and other outcomes. Rivers & Stoneman, (2003) found that researchers who have explored ASD do not have a clear understanding of why some

sibling pairs experience warm, supportive relationships, whereas others experience conflict and isolation. Some researchers (Hastings, 2003a; Ross & Cuskelly, 2006) have reported negative outcomes, such as, loneliness, behavioral difficulties, depression for the typically developing siblings. Other researchers (Kaminsky & Dewey, 2002; Mascha & Doucher, 2006) have found positive outcomes (e.g., less conflict within the relationship, high self-esteem and self-concept) or no evidence of negative effects. Orsmond and Seltzer (2007) investigated adult siblings of individuals with ASD and DS and found that typically developing adult siblings of individuals with ASD reported significantly less contact and less positive effect in the relationship with their sibling with ASD than did the DS group.

Pilowsky et al. (2004) reported that most siblings of individuals with ASD were well adjusted, but emphasized that the stress of having a sibling with ASD cannot be overlooked. Researchers have suggested that the adjustment of siblings of children with ASD is dependent on other demographic factors. Typically developing siblings were found to have more adjustment problems when they were members of smaller families (Kaminsky & Dewey, 2002), had a sibling with ASD with problem behavior (Ross & Cuskelly, 2006), and/or had marital stress in their family (Rivers & Stoneman, 2003). Macks and Reeve (2007) reported that specific demographic characteristics, such as, being male, coming from a family of low socioeconomic status (SES), having only one sibling, being older than the child with ASD) were more likely to impact a sibling of a child with ASD than a sibling of a typically developing child.

In research there have been many mixed findings of how siblings acclimate to living and growing up with a brother or sister with autism there are mixed findings. Siblings are often affected in several ways by having a brother or sister with autism. Most parents reported that the sibling of their child with autism experienced jealousy and or resentment due to attention and

services that their brother or sister were receiving. Other feelings included sadness, fear, and acceptance. Very few siblings were accepting.

Most parents responded by talking to and educating their child about their sibling with autism. Parents also made special days for the sibling or involved the sibling whenever possible in activities with their brother or sister with autism. Mascha and Boucher (2006), found that when the participants were asked what was the greatest part of having a sibling with ASD, they spoke of playing and having fun with their brother or sister.

A lack of support can have a more adverse affect on some siblings than others. Gold (1993) stated that siblings with a brother with ASD who had no one to talk to about having an autistic brother scored significantly high on the CDI, a measure of childhood depression than those who did. Gold (1993) reported that for male siblings of boys with autism the response that "there is nothing good about having a brother with autism" was associated with higher scores on the Child Depression Inventory (Kovacs & Beck 1977).

Bebko, Konstrantareas, and Springer (1987), reported that there is more stress in families of children with autism than in families with children who have other disabilities.
Some studies have reported poor adjustment, higher rates of depression, and poor social competence for siblings of children with autism (Bagenholm & Gillberg, 1991; Gold 1993). There are other studies that have reported siblings of children with autism are well adjusted, with positive self concepts and good social competence (Ferrari 1984; Mates 1990).

Extended Family

Grandparents

Grandparents play a very important role in their grandchild's life. Grandparents provide the meaningful sharing of experiences, an ability to reconnect with the past, fulfillment of family

legacy, and indulgence (Pruchno & Johnson, 1996). Grandparents are also great role models who teach their grandchild how to behave; they are playmates, and secret confidants. The grandparent's interactions with their grandchild are to be visits that are enjoyable provide grandparents with periods of rejuvenation. For some grandparents some of these things are difficult to accomplish with a grandchild who is autistic. Scherman, Gardner, Brown and Shutter (1995), stated that most grandparents did not suspect that their grandchild had a disability before being told. One in every 166 grandparents will become a grandparent to a child with autism (Chakrabarti & Fombonne, 2001). According to Hasting (1997), many grandparents of children with a disability go through a period of mourning. The grandparents grieve the loss for their grandchild and the relationship they expected to have.

Schall (2000) found in a study of three families with children with autism, that all families shared stories of certain levels of rejection by family, kids, and strangers in the community. In this study, almost half of all grandparents were not accepting or understanding of the diagnosis with grandfathers being more than twice as likely as grandmothers to not accept the diagnosis. The maternal grandmother was the most actively involved grandparent in childcare and support. There needs to be more education directed at grandparents, especially grandfathers on the diagnosis. Several parents stated that reading and talking about the diagnosis helped the grandparents slowly come to understand and accept their child. There are several implications of the findings on family involvement. While there were more grandparents actively involved in childcare for the child with autism, there were fewer grandparents than aunts and uncles that were accepting of the diagnosis. Grandparents, if educated more on autism, could be a very strong source of emotional support as are many aunts and uncles of the child.

Long Term Impacts

Social

It is difficult for parents to attend different family and activities due to their child's autism disorder and how people react. According to Gray (1994), the most difficult problems that parents experienced are inappropriate embarrassing public behavior, violence, aggression, poor language skills, and obsessions with eating, inappropriate sexual expressions and destruction in the home.

The challenging behavior patterns of autism may leave parents feeling at a loss in relation to behavior management (Dunlap et al., 1994). Parenting a child with autism has been shown to promote many aspects of family life (e.g. family outings, siblings, relationships and daily living) and in particular any activities that involve social contact (e.g. shopping or visiting family and friends) (Bebko et al., 1987). As a result, parents may withdraw from social, leisure and cultural activities (Kogel et al., 1996) and paid employment. Parents tend to experience problems with making and maintaining relationship (e.g. family and friends), becoming socially isolated (Trute & Hauch 1988) and lonely.

Change is very difficult for a child with autism making family outings sometimes impossible. Transitions include any change in current actions or environment. Simple tasks, such as interrupting playtime to eat a meal, leaving for school, entering a grocery store, coming in from recess, can cause distress for the person with autism. Distress can cause the autistic person to act out physically and verbally. Of course, this is embarrassing for the parent and also stressful when trying to prevent their child from doing physical damage or self-injury. When a family has a child with autism one of the first things parents may notice is that invitations for social gatherings stop coming. Friends without children, or who have children without special needs,

tend to be uncomfortable around the autistic. They usually do not want their children playing with an autistic child, acting at times as if it might be contagious. An autistic child tends to be more withdrawn, frequently playing alone, and may be inappropriate in his play and conduct. An autistic child sometimes makes strange noises or engages in repetitive behaviors that can be scary to other children and adults not used to being around someone with special needs.

Early Identification

Early identification of young children with ASDs can lead to early entry into intervention programs that support improved developmental outcomes (John, Meyers, & the Council on Children with Disabilities, 2007). According to Cox et al. (1999) early identification and diagnosis can enhance the opportunity for effective educational and behavioral intervention, results in reduction of family stress by giving the family a specific techniques and guidance for decision making and improves access to medical a care and other types of support. Early identification promotes early intervention, which increases the potential for improved developmental out comes and reduced costs of care over a period of time. It also helps parents better understand and cope with their child's developmental concerns.

Early Intervention

Early intervention is a group of U.S. government-funded programs carried out by the states. According to Fenske, Zalenski, Krantz, P., & McClannahan, (1985) early intervention helps families and children from birth to age 3 who have a developmental concern or who are at risk to make sure that these children grow to their greatest potential .Services vary by state, but may include: Educational services, Physical therapy, Occupational therapy, Speech therapy, and Family counseling. Early intervention has been associated with improvement in verbal and nonverbal communication, higher intelligence and improved peer interactions (Wiggins et al.,

2006). One of the benefits of early intervention is the positive impacts on the family's ability to interact in a manner that facilitates their child's development and to have a greater understanding of their child's disability and how it interacts with family life (Committee on Children with Disabilities, 1994). Early intervention can improve both developmental functioning and the quality of life for the child with autism and their family
(Eikeseth, Smith, Jahr & Eldevik, 2007).

Early intervention consists of different therapies to: develop communication and social interaction skills; build daily living skills; manage challenging, obsessive, and repetitive behaviors; improve gross and fine motor coordination; develop concentration and attention skills, abilities to imitate and play, and manage sensory difficulties. The most implemented techniques are Applied Behavioral Analysis (Lovaas, 1987) and TEACCH (Treatment and Education of Autistic and Communication Handicapped Children.

Parent Support

Although families experience high levels of stress, many families of individuals with ASD cope successfully with their unique situation (Bayat, 2007; Gray, 2006; Twoy, Connolly, & Novak, 2007). According to Chan & Sigafoos (2001) families that receive informal support from their social networks and formal support from agencies and health care providers are more likely to show positive adjustment. We define coping as strategies and actions that are marshaled to manage a challenging situation and support as the availability of instrumental or emotional support from formal (e.g., agencies) or informal (e.g., friends and relatives) sources.

Chan and Sigafoos (2001) state that respite care, is a second type of support, Respite care refers to a service whereby another adult assumes the role of the parent for children with disabilities for short periods of time on a consistent basis. Chan and Sigafoos (2001) reviewed

studies that evaluated the effect of respite care services used by families of children with developmental disability and concluded that, at least in the short term, respite care can reduce the levels of stress in parents of children with disabilities. They also reported that families who used respite services had decreased levels of stress and were better able to cope with caring for a child with disabilities, relative to those who did not utilize respite care.

Formal support services is third type of support available to parents and families of children with ASD is access to formal support services, such as support groups, health and professional services, and counseling. According to Siklos and Kerns (2006), parents of children with ASD reported that the professionals who provided services to them and their families were more significant than many other types of support, including friendship opportunities for their children.

Mandell and Salzer (2007) found in their research of support groups for parents of children with ASD that supports groups enable contact with other families in similar situations and may reduce social isolation and stress and increase access to information about appropriate and available services. They also emphasized that it is imperative to include support groups for parents of children with ASD as part of the system of care. Furthermore, Shu and Lung (2005) recommended that the primary caregivers of children with ASD need access to regular support group meetings and training services provided during these gatherings to cope with the unique issues they face.

Parent training programs and interventions are great forms of formal support for family members. Many researchers have investigated varying parent training models and paradigms to support families of children with ASD (Brookman-Frazee, 2004; Koegel, Bimbela, & Schreibman, 1996; Tonge et al., 2006). Overall, these studies suggest that parent education is

effective in obtaining positive outcomes for both parents and children. Brookman-Frazee (2004) emphasized that partnerships between parents and professionals often are associated with positive outcomes for both child target behaviors and family quality of life. It is important for parents to know that their level of involvement in their children's intervention programs could influence their well-being. According to Schwichtenberg & Poehlmann (2007), mothers of children with ASD indicated fewer depressive symptoms when their children received more ABA hours per week. However, mothers who tend to spent more hours per week involved in their child's ABA program reported more feelings of personal strain. Trudgeon and Carr (2007) explored the impact of home-based behavior intervention on families of children with ASD and concluded that although parents reported both positive and negative impacts of the program, the sources of support obtained offset the demands of the programs.

It is important for parents to have someone who can support them as the deal with their child’s challenges of autism. Brown, et. al (2003) noted that social support refers to a source of comfort found within group and individual relationships . According to Siklos & Kerns (2006) social support includes support from one's spouse, family and friends. Parents are able to have availability of leisure time to participate in recreational activities, and availability of services and community programs for family members. Parents stress and improve their well-being when they were able to have social and emotional support. Benson (2006) found that informal parent support significantly decreased depression among parents of children with ASD. A method that is found helpful for parents and families of individuals with ASD involves the reliance on an extensive, supportive social network (Dunn et al., 2001). Dunn et. al (2001) reported that accessibility to and use of social support could lead to reductions in stress, depression, and anxiety for mothers of children with autism as well as increased life satisfaction for both parents.

Sibling Support

Smith and Perry (2005) researched the effectiveness of a sibling support group for children with autism. Smith and Perry (2005) found that the siblings' self-concepts and knowledge of autism improved from the beginning to the end of the support group meetings, demonstrating success in meeting the goals of the support group. Support groups are helpful in that they may offer siblings a type of respite. Wolfe et.al (1998), suggested securing a supportive relationship for the typically developing sibling outside of a stressful family system may be an important component of intervention that would benefit siblings of children with pervasive developmental disorder.

Chapter III

Project Audience and Implementation Factors

Development of Project

There are three things that inspired me to create a handbook for parents having a friend with a son diagnosed with autism, being an intern at the CSUN Early Intervention Center and working as a Behavior Therapist.

As a Child Development major I had a classmate whose son was diagnosed with autism. She was great inspiration to me. Through her I learned the improved of not identifying the child by their condition, but to identify the child first and then the condition. For example, a person should say a child with autism instead of an autistic child.

At the Early Intervention Center there were many parents who had children that were diagnosed with a disorder and others who suspect that their child had a disorder. Many parents were not sure what to do or how to help their child improve their speech or social skills. Many times I saw the sadness and confusion in the eyes of many parents and grandparent. As an undergraduate I had to complete a project for my class and thought it would be great for parents to have a handbook that can inform them about their child's disorder.

As a Behavior Therapist many of my clients were children with autism. The parents were eager to see their child improve their skills or even to hear their son or daughter speak for the first. I feel is important for parent to know where they can find help and what the process is that they should take if they suspect that their child has autism.

Intended Audience

This handbook is intended for parents of children recently diagnosed with autism or who suspected of having autism. Even though parents are in a state of relief to know there is a name

for their child's problems, many parents are unsure what steps to take after a child is diagnosed with autism. The Autism Handbook offers concrete answers to parents' questions and concerns. It also provides clear and concise information on autism is provided, including how autism can impact families, early warnings signs, how autism is diagnosed, resources, tips for families and strategies for parents. Parents will receive the information needed to help them advocate for their child and make decisions on various treatments and educational interventions.

Personal Qualifications

The purpose of this project is to provide information for parents whose children either have or are suspected of having autism. This project is to be used to help parents understand what autism spectrum disorder (ASD), recognize signs and symptoms, find resources that are available for their child and their family.

Handbook Outline

What is Autism?

Why is autism referred to as "spectrum disorder?"

What are the Diagnostic Criteria for Autism?

What are the early warning signs for parents to look for?

What do the symptoms of autism consist of?

Prevalence of Autism

Are there other medical conditions associated with Autism?

How is Autism Diagnosed?

What occurs during Screening?

What tools are used in Screening?

What are your child's legal rights?

Chapter IV

Conclusion

Our perception of autism has evolved over the past few years. Sixty years ago autism was nothing more than an unrecognized developmental delay generally grouped in with mental retardation. Today, it is recognized as an independent neurologically based developmental disorder of significance, a major public health problem, and a topic of much research. Researchers have struggled to find a cause for the disorder without great success. It has been stated that there is no cure for autism, but there are numerous treatments that have been developed that help children with autism to maximize their potential to learn and become socially fluent, no matter how impaired they may be.

Suggestions for Future Work

Since autism does not cease at infancy, it would be great to create a series of handbooks for parents. The two handbooks that would be created are an autism handbook for toddler and an autism handbook for adults. This would help parents and their adult children to continue to find resources, support and information as they go through different stages in their lives.

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Appendix

Autism: A Handbook

For

Parents

Table of Contents

What is Autism?

Autism is a complex neurological disorder that appears during the first three years of life. It leads to significant impairment in three areas of functioning: social interaction, communication and repetitive behavior. Autism is a one of five pervasive developmental disorders (PPD) that are known as autism spectrum disorders (ASDs). Autism is a disorder of the brain. It is known as a "developmental disorder because it affect how a child develops" and their ability to interact, communicate, relate, play, imagine and learn. You cannot get autism by being near other people who has autism. Autism affects people from all ethnic group and socioeconomic backgrounds. Autism is more common than cystic fibrosis, childhood cancer and multiple sclerosis. It is the third most common developmental disability following mental retardation and cerebral palsy. Every person is affected by autism differently. Some children will show all characteristics while other only display a few.

The signs and symptoms are seen in early childhood. Autism is given the term spectrum disorder because of the wide range of intensity, symptoms and behaviors, types of disorders, and considerable individual variation. Children with ASD may have a lack of interest and ability to interact, limited ability to communicate, and show repetitive behaviors and distress over changes, which is common in children with classic autism, or Autistic Disorder. On the other end of the spectrum are children with a high-functioning form of autism who may have unusual social, language, and play skills, as in Asperger Syndrome. The autism spectrum consists of the following disorders: Autistic Disorder or Classic Autism, Rett's Disorder or Rett Syndrome, Childhood Disintegrative Disorder, Asperger's Disorder or Asperger Syndrome, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS).

Why is autism referred to as a "spectrum disorder?"

The term spectrum is important to understanding autism because of the wide range of intensity, symptoms and behaviors, types of disorders, and considerable individual variation. The autism spectrum consists of the following disorders: Autistic Disorder or Classic Autism, Rett's Disorder or Rett Syndrome, Childhood Disintegrative Disorder, Asperger's Disorder or Asperger Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).

Children with ASD may have a lack of interest and ability to interact, limited ability to communicate, and show repetitive behaviors and distress over changes, as in the case of many with classic autism, or Autistic Disorder. On the other end of the spectrum are children with a high-functioning form of autism who may have unusual social, language, and play skills, as in Asperger Syndrome.

What are the Diagnostic Criteria of Autism?

The DSM -IV states the criteria for Autistic Disorder is the following:

A. A total of six (or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

   (1) Qualitative impairment in social interaction, as manifested by at least two of the following:

      (a) marked impairment in the use of multiple nonverbal behavior such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

      (b) failure to develop peer relationships appropriate to developmental level

      (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, brining, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) Qualitative impairment in communication as manifested by at least one of the following:

(a) delay in, or lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either

(b) apparently inflexible adhere to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motto mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with Onset prior to age 3 years (1) social interaction, (2) language as used to social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

What are the early warning signs for parents to look for?

Early Indicators of Autism Spectrum Disorders

- Does not babble, point, or make meaningful gestures by 1 year of age
- Does not speak one word by 16 months
- Does not combine two words by 2 years
- Does not respond to name
- Loses language or social skills
- Poor eye contact
- Doesn’t seem to know how to play with toys or excessively lines up toys or other objects
- Is attached to one particular toy or object
- Doesn't smile or interact joyfully
- At times seems to be hearing impaired
- May not be cuddly or seek physical comfort for parents or caregiver
- Aggressive behavior
- Abnormal eating habits

What do the symptoms of autism consist of?

Autism has three distinctive behaviors. Children with autism tend to have difficulties with social interactions, verbal and nonverbal communication. They also have repetitive behaviors and obsessive interest. These symptoms may vary from moderate to severe.

Social Interaction problems

Social Issues include:

- Failure to respond to their name
- Failure to respond to parents’ voice

- Avoiding eye-contact
- Preferring to play alone
- Does not share interest with others
- Has flat or inappropriate facial expressions
- Does not understand personal space or boundaries
- Has trouble understanding other people feelings
- Shows lack of empathy
- Avoiding or resist physical contact

Communication problems: All children with autism experience language and communication difficulties, although there are considerable differences in language ability among individuals. Some are non-verbal while others may have extensive language with deficits in the area of pragmatics (the social use of language). People with autism may seem caught up in a private world in this is not a deliberate act but rather a failure to communicate, in which communication is insignificant

Language difficulties that may be present in children with autism include:

- Uses behavior to express feelings
- Lack of development or delayed development of speech
- Talks in flat or sing-song voice
- Expresses emotions inappropriately
- Uses few or no gestures
- Does not understand jokes or teasing
- Gives unrelated answers to questions
- Refers to themselves by name instead of “I” or “me”

- Difficulties with non-verbal communication
- Inappropriate facial expressions
- Lack of eye contact
- Odd body postures
- Indifferent in mutual or shared focus of attention
- Delay in or lack of expressive language skills
- Unusual pitch or tone
- • Repetitive and peculiar speech patterns
- Echolalia speech, immediate or delayed exact repetition of the others words or phrase
- Appears to be non-meaningful, but may indicate an attempt to communicate
- Restricted vocabulary
- Mainly uses nouns
- Limited in social functions
- Repeatedly talks about one topic and has difficulty changing topics
- Problems initiating the communication
- Inability to maintain conversation on a topic
- Inappropriate interrupting

Unusual Interest and Behaviors

Many people with autism tend to have many unusual interests and behaviors.

- Limited interest in activities or play
- Insistence on sameness and resistance to change (eating only certain foods or going places in the same route)
- May be self-injurious (head banging)

- May be resistant to change
- May anger easily
- Stereotypic and repetitive motor mannerisms, such as hand flapping, finger flicking, clapping, rocking, spinning, walking on tiptoes, spinning objects.
- Preoccupation with parts of objects.
- Fascination with movement, such as the spinning of a fan, or turning wheels on toys.
- Restricted range of interests, and an obsession with one particular interest or object.

Prevalence of Autism

In 2007 the Centers for Disease Control (CDC) found that the rate is higher than the rates found from studies conducted in the United States during the 1980s and early 1990s (survey based on data from 2000 and 2002). The CDC survey assigned a diagnosis of autism spectrum disorder based on health and school records of 8 year olds in 14 communities throughout the U.S. Debate continues about whether this represents a true increase in the prevalence of autism. Changes in the criteria used to diagnose autism, along with increased recognition of the disorder by professionals and the public may all be contributing factors. Nonetheless, the CDC report confirms other recent epidemiologic studies documenting that more children are being diagnosed with an ASD than ever before.

Data from an earlier report of the CDC's Atlanta-based program found the rate of autism spectrum disorder was 3.4 per 1,000 for children 3 to 10 years of age. Summarizing this and several other major studies on autism prevalence, CDC estimates that 2-6 per 1,000 (from 1 in 500 to 1 in 150) children have an ASD. The risk is 3-4 times higher in males than females. Compared to the prevalence of other childhood conditions, this rate is lower than the rate of mental retardation (9.7 per 1,000 children), but higher than the rates for cerebral palsy (2.8 per

1,000 children), hearing loss (1.1 per 1,000 children), and vision impairment (0.9 per 1,000 children).The CDC notes that these studies do not provide a national estimate.

According to the Center for Disease Control (2009), in the United States, there is an average of 1 in 110 births that have been diagnosed with an autism spectrum disorder. Of this result 1 in 70 are boys. Autism is four times more common in boys than in girls.

According to the National Institute of Mental Health (NIMH) and the Centers for Disease Control and Prevention (CDC), some form of autism affects 2 to 6 of every 1,000 children, with the most recent statistic being 1 in 110. ASDs are four times more common in boys than in girls, although Rett Syndrome has only been diagnosed in girls.

Are there other medical conditions associated with Autism?

Anxiety disorders

Anxiety is a real and serious problem for many people on the autism spectrum. Common phobias for children with ASD include the fear of certain places or situations, the fear of medically related people, places, or things, and the fear of loud noises. According to Joshi et al. (2010) Social Phobia or Social Anxiety Disorder is seen in approximately 7.4% of individuals with ASD, but is more common in higher-functioning individuals who have a desire for social interactions, but are also aware of their social deficits.

Fragile X Syndrome

Fragile X Syndrome is an inherited condition due to abnormality of the X chromosome. This syndrome is commonly found in males. The characteristics are learning difficulties of various levels, over-sensitivity to sound and touch, repetitive routines, hyperactivity, poor attention, and abnormality of speech. In some cases the autistic type of social impairments occurs. Chromosome examination is now a standard part of investigation of autistic behavior.

Gastrointestinal Disorder

Gastrointestinal (GI) disorders are among the most common medical conditions associated with autism. These issues range from chronic constipation or diarrhea to inflammatory bowel conditions. They can affect persons of any age. But in the context of autism, they have been most studied in children. It has been claimed that up to fifty percent of children with autism experience persistent gastrointestinal tract problems, ranging from mild to moderate degrees of inflammation in both the upper and lower intestinal tract. Constipation, often with overflow, or involuntary defecation, is often associated with developmental disorders in children, and is often difficult to resolve, especially among those with behavioral and communication problems.

Laudau-Kleffner Syndrome

This is a disorder that is found in children between the ages of three and seven years old. It is characterized by sudden or gradual development of aphasia (the inability to express or understand language) and an abnormal electroencephalogram (EEG). Laudau- Kleffner Syndrome can be difficult to diagnose and it can easily be misdiagnosed as autism, pervasive developmental disorder, hearing impairment, learning disability, auditory/verbal processing disorder, attention deficit disorder, mental retardation, childhood schizophrenia, or emotional/behavioral problems

Pica

Pica is an abnormal craving for non-edible substances. The word “pica” comes from the Latin word for magpie, a bird known for eating anything in its path. Children between the age of two and three, and people with developmental disabilities display pica behavior such as consuming dirt, hair, foam, paper. Others cravings include clay, paint chips, plaster chalk cornstarch, feces, ice, glue, hair, buttons, papers, toothpaste, soap and laundry starch

Pica is most common in people with developmental disabilities, including autism and mental retardation, and in children between the ages of 2 and 3. Pica also may surface in children who've had a brain injury affecting their development. It can also be a problem for some pregnant women, as well as people with epilepsy. For a true diagnosis of pica, the child should be craving and eating these things for at least a month. Although common in infants and toddlers, most children outgrow pica by the time they are about three years old.

Seizures and epilepsy

Seizures are relatively common in children and adults on the autism spectrum. Independently, autism and epilepsy (seizures of unknown cause), each occur in around 1 percent of the general population. But epilepsy rates among persons with autism range from 20 to 40 percent, with the highest rates among those who are the most severely impaired by autism's core symptoms. Conversely, about 5 percent of children who develop epilepsy in childhood go on to develop autism.

Sleep Disorders

Children with autism tend to have a hard time with getting a good night's sleep. Some children walk up in the middle of the night, while other have a hard time falling asleep. They easily wake up during the night by the slightest noise or shifting of a blanket. Melatonin is a hormone that regulates sleep cycles. Autistic children have been found to have abnormal levels of melatonin, or release melatonin at the wrong time during the day. These problems make it harder for them to pay attention, reduce their ability to function, and lead to poor behavior. This can also cause great stress and poor health for family members. These types of sleep problems can be treated by creating a sleep schedule or creating a bedtime routine.

Tourette Syndrome

A motor disorder characterized by motor and verbal tics. Tics are uncontrolled, repetitive movements or speech. Tics can be simple twitches, more complex movements, or even complete phrases. The person with Tourette Syndrome is usually unable to control tics although sometimes they can be suppressed briefly (similar to stifling a sneeze). Tics are usually worse when the person is under stress, even if the stress is from trying to control the tics.

Tuberous sclerosis

Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs. It has a consistently strong association with ASD. One to 4 percent of people with ASD also have tuberous sclerosis.

How is Autism Diagnosed?

The diagnosis of autism is usually first suspected by parents or professional who are in touch with the child, such as teachers, pediatricians, or speech therapists. ASD diagnosis is often a two-stage process. The first stage involves general developmental screening during well-child checkups with a pediatrician or an early childhood health care provider. Children who show some developmental problems are referred for additional evaluation. The second stage involves a thorough evaluation by a team of doctors and other health professionals with a wide range of specialties. The evaluation may include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments. In this stage, a child may be diagnosed as having autism or be told if it is another type developmental disorder

What occurs during Screening?

Screening is defined as a brief, formal, standardized evaluation used to identify

unsuspected deviations from normal patterns of development. A screening instrument enables detection of conditions/concerns that may not be readily apparent without screening. Screening does not provide a diagnosis; it helps to determine whether additional investigation (eg, a diagnostic evaluation) by clinicians with special expertise in developmental pediatrics is necessary. Effective screening requires that results from standardized screening tests be considered in conjunction with clinical judgment.

Currently, the screening tools for Autism consist of 1) parent questionnaires and 2) medical worker observation forms and activity set objectives which allow for modifications to the testing based on age and need. Screening is a way to monitor development--it is not the same as a diagnosis. The purpose of screening is to identify children who *might* have a developmental delay or disorder. Identifying atypical or delayed development as early as possible is important so that children can access appropriate interventions. Screening tools are often developed for a specific problem or condition. The American Academy of Pediatrics recommends screening for autism at both the 18-month and 24-month well-child visits. The screening process should involves three steps: 1) completion of a questionnaire by caregivers to assess social and communication development, 2) direct observation by the specialist and 3) review of clinical history.

What tools are used in Screening?

Ages and Stages Questionnaires (ASQ-3TM)

ASQ is a tool for screening infants and young children for developmental delays during the first five years of life. This test focuses on communication, gross and fine motor skills, social skills, and problem solving. ASQ looks at strengths and trouble spots, educates parents about developmental milestones.

Autism Behavioral Checklist of the Autism Screening Instrument for Educational Planning (abc-asiep-3).

The ABC looks at five aspects of behavior and is used to conduct a structured interview with a parent or other caregiver. It is less effective with high functioning forms of autism. ABC is a subtest of the longer ASIEP and is used alone or in conjunction with four other ASIEP subtests. It consists of fifty-seven behavior descriptions in five areas, and is used to conduct a structured interview with a parent or other caregiver. The score is presented as a scale indicating the existence and severity of autistic behavior, as contrasted to other disorders. It is less effective with high-functioning forms of autism, such as PDD-NOS and atypical PDD, than with "classical" autism.

Autism Diagnostic Interview Revised (ADI-R)

The Autism Diagnostic Interview-Revised (ADI-R) is a structured interview conducted with the parents of individuals who have been referred for the evaluation of possible autism or autism spectrum disorders. The interview, used by researchers and clinicians for decades, can be used for diagnostic purposes for anyone with a mental age of at least 18 months and measures behavior in the areas of reciprocal social interaction, communication and language, and patterns of behavior. It is a combination of two earlier instruments: the Autism Diagnostic Observation Schedule a schedule intended for adults and children with language skills at a minimum of the three-year-old level, and the Pre-Linguistic Autism Diagnostic Observation Scale, a schedule intended for children with limited or no language, as well as additional items developed for verbally fluent, high-functioning adolescents and adults

The interview covers the child's developmental history. It is usually conducted in an office, home or other quiet setting by a psychiatrist or other trained and licensed professional,

and generally takes one to two hours. Caregivers are asked 93 questions, spanning the three main behavioral areas, about either the child's current behavior or behavior at a certain point in time. The interview is divided into five sections: opening questions, communication questions, social development and play questions, repetitive and restricted behavior questions, and questions about general behavior problems. The questions are very open-ended and the investigator is able to obtain all of the information required to determine a valid rating for each behavior. Having parents taking part in this interview helps them obtain a better understanding of Autism Spectrum Disorder and the factors that lead to a diagnosis. Clinician are required to view training videos and attend workshops for administration and scoring, in order to use the instrument. Researchers are required to attend specific research training and establish their reliability in using the ADI-R in order to use it for research purposes.

Autism Diagnostic Observation Schedule (ADOS)

The Autism Diagnostic Observation Schedule can be a valuable instrument when it comes to evaluating communication and socialization characteristics commonly associated with autism. The diagnostic tool uses target behaviors to gauge the child's responses during specific tasks. The test is both valid and reliable. The test is very useful tool because it can accommodate people of different ages, and of different abilities. The test is as effective for nonverbal individuals as it is for those who speak fluently. It is appropriate for toddlers, children and adults.

The ADOS is ideal for professionals who are familiar with autistic disorders, and who have training in administering the test. The test can be instrumental in clinical, medical and evaluative settings. Professionals who use the assessment tool include: Physicians, Occupational therapists, Researchers, Speech-language pathologists, Psychiatrists and Social workers. ADOS

is an assessment measure that typically takes about 30 to 40 minutes to complete. The test evaluates the individual's responses in the realms of communication, imaginative use of objects, social interaction and play skills.

Childhood Autism Rating Scale (CARS)

The CARS is a direct-observation format for evaluating the behavior of children and adolescents. Results can be scored on two scales, one with a range from age appropriate to severely abnormal, the other with a range from not autistic to mild-moderate autistic to severely autistic.

Checklist of Autism in Toddlers (CHAT)

The CHAT is a screening tool developed for pediatricians to use at the eighteenth- month check up. Clinicians complete five items based on observation and as parents to answer yes or no to an additional nine items.

Modified Checklist for Autism Toddlers (M-CHAT)

The M-CHAT is a revised CHAT with additional questions. The M-CHAT is an autism screening tool designed to identify children 16 to 30 months of age who should receive a more thorough assessment for possible early signs of autism spectrum disorder (ASD) or developmental delay.

Parent interview for Autism (PIA)

The Parent Interview for Autism is a structured interview containing 118 items, arranged in 11 dimensions assessing various aspects of social behaviour, communicative functioning, repetitive activities and sensory behaviours. It is designed to obtain diagnostically relevant information from parents of young children suspected of having autism and takes around 45 minutes to administer.

Social Communication Questionnaire (SCQ)

The SCQ was created by autism researchers Michael Rutter, M.D., FRS, Anthony Bailey, M.D., and Catherine Lord, Ph.D. It consists of just forty yes-or-no questions, which a parent can complete in around ten minutes. It helps to evaluate communication skills and social functioning in children who may have autism or autism spectrum disorders. The questionnaire can be used to evaluate anyone over age 4, as long as his or her mental age exceeds 2 years old. Usually, the SCQ is used as a screening instrument to help identify which children may have an autism spectrum disorder. It provides valuable information on a child's body movements, use of language or gestures, and style of interacting. It is not meant to provide a detailed diagnosis, but to indicate whether a child needs a more careful and in-depth evaluation.

Social Communication and Symbolic Behavior Scales (CSBS)

Social Communication and Symbolic Behavior Scales is a parent checklist to screen communication skills and social function of children who may have autism or autism spectrum disorders. It examines communication, social-affective, and symbolic abilities of children whose functional communication age is between 8 months and 2 years. It helps to establish a profile of communication, social-affective, and symbolic functioning to monitor changes in behavior and plan treatment. The CSBS uses standard but flexible format for sampling behavior. Materials include action-based toys to elicit spontaneous communication, books designed for young children, and play materials that assess how a child uses and plays with objects symbolically and constructively.

What are your child's legal rights?

Under the U.S. federal law known as the Individuals with Disabilities Education Act (IDEA), children with disabilities—including those with autism spectrum disorders—are eligible

for a range of free or low-cost services. Under this provision, children in need and their families may receive medical evaluations, psychological services, speech therapy, physical therapy, parent counseling and training, assisted technology devices, and other specialized services.

Children under the age of 10 do not need an autism diagnosis to receive free services under IDEA. If they are experiencing a developmental delay (including delays in communication or social development), they are automatically eligible for early intervention and special education services.

Is there a cure for Autism?

There is no cure for autism, but there are many types of treatment that may allow for relatively normal development in the child and reduce undesirable behaviors. Treatment is successful when it is geared towards the child's particular needs. Therapies, or interventions, are designed to remedy specific symptoms in each individual. The best-studied therapies include educational/behavioral and medical interventions. Although these interventions do not cure autism, they often bring about substantial improvement.

What are the different types of methods used to treat Autism?

Applied Behavior Analysis (ABA)

Applied Behavioral Analysis, is a way of teaching and reinforcing appropriate behaviors. Psychologist Ivar Lovaas of the Lovaas Institute for Early Intervention at UCLA created this technique. Professionals use the ABA techniques a basis for designing behavioral interventions for individuals with autism

The focus of ABA is to continually engaging the child and discouraging him or her from wondering off to activities such as repetitive play or self- stimulation, which is as known as stimming. There should breaks, rewards and opportunities for play because this technique should

not be unpleasant for the child. The child is rewarded if the task is done correct. The child is not reinforced for incorrect answers

Discrete Trial Training (DTT)

Discrete trial training is an intensive treatment designed to assist individuals with developmental disabilities, such as autism. It involves one-on-one intensive drills for learning such things as colors, shapes, and items in the environment (Myles & Simpson, 1990). It involves directly training a variety of skills that individuals with disabilities may not pick up naturally. Programs often start by training pre-learning skills (sitting, attending, looking at trainer), social skills (looking at people, talking and interacting with them appropriately), safety skills (ability to state name, address, and phone number) and basic concepts (colors, letters, numbers). Children who are non-verbal may be trained to speak, use sign language, or use other communication devices. After these basics are mastered, higher-level skills are trained.

Discrete trial training is conducted using intensive drills of selected materials. A specific behavior is prompted or guided, and children receive reinforcement for proper responses (Harris and Delmolino, 2002). Initially, basic reinforcers such as candy, soda, or other edibles are utilized.

DIR ® /Floortime ™

Dr. Stanley Greenspan, a child psychiatrist, developed a form of play therapy that uses interactions and relationships to reach children with developmental delays and autism. This method is called the **D**evelopmental, **I**ndividual-Difference, **R**elationship-Based model. Floortime is based on the theory that autism is caused by problems with brain processing that affect a child's relationships and senses. It stresses emotional bonding and requires the parent’s or caregiver’s role to follow the child's lead and help him develop social interaction and

communication skills (Greenspan & Wieder, 1997). This program requires at least four hours a day to be effective.

Picture Exchange Communication System (PECS)

Picture Exchange Communication System (PECS) was developed in 1985 by Lori Frost and Andy Bondy. PECS is an alternative communication intervention package for individuals with autism spectrum disorder and related developmental disabilities. The PECS teaching protocol is based on B.F. Skinner's book, *Verbal Behavior*.

PECS is used for children, adolescents and adults who have cognitive, communication and physical difficulties (Cannella-Malone, Fant, & Tullis, 2010). The first phase of PECS, the child or person learns how to communicate by exchanging a single picture for an item or activity they want. The second phase allows the child to learn how to generalize their new skill with the single picture by using it in different places and with different people. The third phase is picture discrimination, in which, the child or person would learn how to select two or more pictures to as for their favorite things. The fourth phase would teach the child or person how to construct a simple sentence using one of their pictures. The fifth phase teaches them how to answer questions using their pictures. In the sixth and final phase the learn how to comment using their pictures (Bondy& Frost 1994).

Pivotal Response Training® (PRT)

Pivotal response training was developed by Dr. Robert L. Koegel and Dr. Lynn Kern Koegel, at the University of California, Santa Barbara. It was first called the Natural Language Paradigm (NLP), which had been in development since the 1970s. Pivotal response training is a behavioral treatment intervention based on the principles of applied behavioral analysis (ABA). PRT is used to teach language, decrease disruptive/self-stimulatory behaviors and increase social,

communication and academic skills by focusing on critical, or "pivotal," behaviors that affect a wide range of behaviors Psychologists, special education teachers, and speech therapists are trained in PRT.

The four pivotal areas of a child's development that pivotal response training focuses on improving the child's motivation, helping them to respond to multiple cues, increase their self-management, and social initiations (Koegel & Koegel, 2006). The primary pivotal behaviors that are focused on for children with autism are motivation and their response to multiple cues. Pivotal behaviors are those behaviors that are central to wide areas of a child's functioning, and when promoted, they are believed to produce improvement in many non-targeted behaviors (Stahmer, 1995). The main goal of PRT is to produce positive changes in the pivotal behaviors, leading to improvement in communication skills, play skills, social behaviors and the child's ability to monitor his or her own behavior.

Relationship Development Intervention (RDI)

Relationship Development Intervention (RDI) Program is a parent-based clinical treatment for individuals with autism spectrum and other relationship-based disorders. The RDI Program is based upon the model of Experience Sharing developed by Steven Gutstein Ph.D. Dr. Gutstein studied the means by which typical children become competent in the world of emotional relationships. The primary goal of the RDI Program is to systematically teach the motivation for and skills of Experience Sharing interaction (Gutstein, Burgess, & Montfort 2007). The RDI Program provides a path for people on the Autism Spectrum to learn friendship, empathy and a love of sharing their world with others.

Sensory Integration

Sensory Integration (SI) is a therapeutic approach, which was developed by Dr. Jean

Ayres incorporating the vestibular, proprioceptive and tactile systems. This input facilitates the development of the nervous system. It is through the familiar sensory systems of touch, sight, smell, taste, and hearing that we receive input and information about our world. This information is taken in by the vestibular, proprioceptive and tactile systems which sorts and connects the information to the environment (Schaaf & Miller, 2005). Additionally, information is processed combining with the perception of position in space, an awareness of body posture, and the ability to discriminate and plan motor movements.

Children diagnosed with disorders in the autism spectrum commonly experience problems with sensory integration. These problems can vary from low arousal levels and a decreased sensitivity to visual or auditory input, to poor organizational and motor planning skills, to hypersensitivity. Sensory integration is most commonly used by Occupational Therapists however many speech and language pathologists

Social Stories

Social Stories were developed in 1991 by Carol Gray as a tool for teaching social skills to children with autism. Social stories teach children with autism how to interact with others. Before developing a social story it is important to know how the child interacts socially and find out what situations and circumstances are difficult. Social stories teach appropriate behaviors in the form of a story. Through a story developed about a particular situation or event, the child is provided with as much information as possible to help him or her understand the expected or appropriate response (Gray & Garand, 1993). The stories contain three sentence types: descriptive sentences addressing the where, who, what and why of the situation; perspective sentences that provide some understanding of the thoughts and emotions of others; and directive sentences that suggest a response (Scattone, Wilczynski, Edwards, & Rabian, 2002) The stories

can be written by anyone, are specific to the child's needs, and are written in the first person, present tense. Pictures, photographs or music can also be incorporated in social stories.

TEACCH Method

TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) was developed by psychologist Eric Schopler at the University of North Carolina in the 1960s. TEACCH focuses on tailoring individual programs, building on existing skills and interests. It also focuses on supporting functional behavior in daily routines through the use of visual and environmental cues (Lovaas, 1981). It relies heavily on visual learning, strength for many children with autism and PDD. The children use schedules made up of pictures and/or words to order their day and to help them move smoothly between activities. Children with autism may find it difficult to make transitions between activities and places without schedules.

TEACCH uses several techniques and methods like Applied Behavior Analysis (ABA) and Developmental Individual Difference, Relation- Based model. TEACCH provides clinical services such as diagnostic evaluations, parent training and parent support groups, social play and recreation groups, individual counseling for higher-functioning clients, and supported employment. In addition, TEACCH conducts training nationally and internationally and provides consultation for teachers, residential care providers, and other professionals from a variety of disciplines. The TEACCH program includes an array of services such as evaluations, parent training and support groups, social and recreation groups, and counseling (Panerai, Ferrante, Zinagle, 2002).

Other Interventions and Therapies

Speech Therapy

Language deficits are one of the core aspects of autism, and speech therapy provides professional help and guidance in communication development for individuals with autism.

Occupational Therapy

Although not listed in the DSM IV as one of the recognized deficits in autism, clinicians have found that many children with autism have significant hypotonia. Others have motor-planning problems affecting their ability to perform fine-motor tasks such as writing. Occupational therapists are an essential part of the treatment team working on these deficits and primarily work on improving functional skills.

Physical Therapy

Some children qualify for physical therapy because their motor-planning and hypotonia affect their ability to move and walk. Motor delays can compound difficulties for children with other developmental problems.

Acronyms

ABA - Applied Behavior Analysis

ASA- Autism Society of America

ASD - Autistic Spectrum Disorder

CAN – Cure Autism Now

CDC - Centers for Disease Control and Prevention

CARS – Child Autism Rating Scale

CHAT- Checklist for Autism in Toddlers

DAN - Defeat Autism Now

DSM – IV- TR - Diagnostic Statistical Manual, 4th Edition Revised

DTT - Discrete Trail Training

EI - Early Intervention

FEAT – Families for Early Treatment of Autism

GFCF- Gluten Free / Casein Free

IDEA - Individual with Disabilities Education Act

IEP - Individualized Education Plan

IFSP - Individualized Family Service Plan

NICHCY - National Information Center for Children and Youth with Disabilities

NIH – National Institute of Health

OT – Occupational Therapist

PECS – Picture Exchange Communication System

PDD - Pervasive Developmental Disorder

PRT – Pivotal Response Training

SIB – Self - Injurious Behavior

SLP – Speech and Language Pathologist

TEACCH - Treatment and Education of Autistic and Related Communication Handicapped Children

Strategies for Parents

The following is a list by Rachel Evans of 15 different autism strategy suggestions parents can utilize to help them manage their children with autism spectrum disorders:

1. Provide a predictable environment and daily routine

2. Prepare your child in advance for any changes that need to occur to the routine, don't spring surprises on them. Keep in mind changes should only be made when absolutely necessary.

3. Activities should have structure.

4. Distractions should be kept to a minimum, especially when communicating, so don't try competing with the TV or lots of background noise when giving instructions.

5. Ensure you have your child's full attention when trying to communicate with them.

6. When giving instructions they should be simple and direct so there is no room for misunderstandings.

7. When instructions are given, you need to allow enough time for your child to process them. Autism strategies require patience - don't rush your child.

8. Try using visual aids like flash cards or picture books when communicating as these can help get your message across and cement understanding.

9. Try to be as consistent as possible with everything you do involving your autistic child. This includes punishments.

10. If an autistic individual is not coping, he/she requires a "safe" place where they can retreat in order to calm down and de-stress.

11. If your child is not coping with a situation, consider if underlying causes (I.E. confusion, stress, fear, pain or over-stimulation) could be a factor and try to remove that cause.

12. When the stress levels of an autistic have reduced, encourage them to return to group activities or situations.

13. Speak to the school to see if a buddy system could be introduced to help provide academic and social support. This involves pairing autistic kids with non-autistic peers.

14. Before attempting to alter or discourage a behavior that you think is inappropriate, carefully consider if this is necessary, as the behavior you are trying to diminish may be replaced by something worse.

15. Don't take autism behaviors personally, find ways to de-stress yourself and remember that laughter is often the best medicine when you're at your wits end.

For discover more autism coping strategies sign up for the free newsletter below.

In addition, parents need to keep in mind that education is one of the best autism strategies they can apply in their efforts to manage their child's autism. The more information one knows about autism, the easier it will be to cope, understand the needs of autistics, and help provide them with the best environment to grow up in.

Fifteen Tips for Your Family

As a result of her work with many families who deal so gracefully with the challenges of autism,

Family Therapist, Kathryn Smerling, Ph.D., offers these five tips for parents, five for siblings and five for extended family members:

5 Tips for Parents

- **Learn to be the best advocate you can be for your child**. Be informed. Take advantage of all the services that are available to you in your community. You will meet practitioners and providers who can educate you and help you. You will gather great strength from the people you meet.
- **Don't push your feelings away.** Talk about them. You may feel both ambivalent and angry. Those are emotions to be expected. It's OK to feel conflicting emotions. Try to direct your anger towards the disorder and not towards your loved ones. When you find yourself arguing with your spouse over an autism related issue, try to remember that this topic is painful for both of you; and be careful not to get mad at each other when it really is the autism that has you so upset and angry.
- **Try to have some semblance of an adult life.** Be careful to not let autism consume every waking hour of your life. Spend quality time with your typically developing children and your spouse, and refrain from constantly talking about autism. Everyone in your family needs support, and to be happy despite the circumstances.
- **Appreciate the small victories your child may achieve.** Love your child and take great pride in each small accomplishment. Focus on what they can do instead of making comparisons with a typically developing child. Love them for who they are rather than what they should be.
- **Get involved with the Autism community.** Don't underestimate the power of "community". You may be the captain of your team, but you can't do everything yourself.

Make friends with other parents who have children with autism. By meeting other parents you will have the support of families who understand your day to day challenges. Getting involved with autism advocacy is empowering and productive. You will be doing something for yourself as well as your child by being proactive.

5 Tips for Brothers & Sisters

- **Remember that you are not alone!** Every family is confronted with life's challenges… and yes, autism is challenging… but, if you look closely, nearly everyone has something difficult to face in their families.
- **Be proud of your brother or sister**. Learn to talk about autism and be open and comfortable describing the disorder to others. If you are comfortable with the topic…they will be comfortable too. If you are embarrassed by your brother or sister, your friends will sense this and it will make it awkward for them. If you talk openly to your friends about autism, they will become comfortable. But, like everyone else, sometimes you will love your brother or sister, and sometimes you will hate them. It's okay to feel your feelings. And, often it's easier when you have a professional counselor to help you understand them – someone special who is here just for you! Love your brother or sister the way they are.
- **Don't Be Angry.** While it is OK to be sad that you have a brother or sister affected by autism it doesn't help to be upset and angry for extended periods of time. Your anger doesn't change the situation; it only makes you unhappier. Remember your Mom and Dad may have those feelings too.
- **Spend time with your Mom and Dad alone**. Doing things together as a family with and

without your brother or sister strengthens your family bond. It's OK for you to want alone time. Having a family member with autism can often be very time consuming, and attention grabbing. You need to feel important too. Remember, even if your brother or sister didn't have autism, you would still need alone time with Mom and Dad.

- **Find an activity you can do with your brother or sister.** You will find it rewarding to connect with your brother or sister, even if it is just putting a simple puzzle together. No matter how impaired they may be, doing something together creates a closeness. They will look forward to these shared activities and greet you with a special smile.

5 Tips for Grandparents and Extended Family

Family members have a lot to offer. Each family member is able to offer the things they have learned to do best over time. Ask how you can be helpful to your family.

Your efforts will be appreciated whether it means taking care of the child so that the parents can go out to dinner, or raising money for the special school that helps your family's child. Organize a lunch, a theatre benefit, a carnival, or a card game. It will warm your family's hearts to know that you are pitching in to create support and closeness.

- **Seek out your own support.** If you find yourself having a difficult time accepting and dealing with the fact that your loved one has autism, seek out your own support. Your family may not be able to provide you with that kind of support so you must be considerate and look elsewhere. In this way you can be stronger for them, helping with the many challenges they face.
- **Be open and honest about the disorder**. The more you talk about the matter, the better you will feel. Your friends and family can become your support system…but only if you share your thoughts with them. It may be hard to talk about it at first, but as time goes on

it will be easier. In the end your experience with autism will end up teaching you and your family profound life lessons.

- **Put judgment aside.** Consider your family's feelings and be supportive. Respect the decisions they make for their child with autism. They are working very hard to explore and research all options, and are typically coming to well thought out conclusions. Try not to compare children (this goes for typically developing kids as well). Children with autism can be brought up to achieve their personal best.
- **Learn more about Autism**. It affects people of all social and economic standing. There is promising research, with many possibilities for the future. Share that sense of hope with your family while educating yourself about the best ways to help manage this disorder.
- **Carve out special time for each child.** You can enjoy special moments with both typically developing family members and the family member with autism. Yes, they may be different but both children look forward to spending time with you. Children with autism thrive on routines, so find one thing that you can do together that is structured, even if it is simply going to a park for fifteen minutes. If you go to the same park every week, chances are over time that activity will become easier and easier…it just takes time and patience. If you are having a difficult time trying to determine what you can do, ask your family. They will sincerely appreciate that you are making.

Resources

Eastern Los Angeles Regional Center
1000 South Fremont
Alhambra, CA 91802-7916
Mailing Address: P.O. Box 7916
Alhambra, CA 91802-7916

Frank D. Lanterman Regional Center
3303 Wilshire Boulevard, Suite 700
Los Angeles, CA 90010

North Los Angeles County Regional Center
15400 Sherman Way, Suite 170
Van Nuys, CA 91406-4211

San Gabriel/ Pomona Regional Center
761 Corporate Center Drive
Pomona, CA 91768

South Central Los Angeles Regional Center
650 West Adams Boulevard, Suite 200
Los Angeles, CA 90007-2545

Suggested Readings

Voices from the Spectrum: Parents, grandparents, siblings, people with autism, and professionals share their wisdom by Cindy N. Ariel and Robert A. Naseef

A picture's worth: PECS and other visual communication strategies in autism by Andy Bondy and Lori Frost

The pyramid approach to education in autism by Andy S. Bondy and Beth Sulzer- Azaroff

Visual supports for people with autism by Marlene J. Cohen and Donna L. Sloan

Incentives for change: Motivating people with autism spectrum disorders to learn and gain independence by Lara Delmolino and Sandra L. Harris

Decreasing behaviors of persons with severe retardation and autism by Richard M. Foxx

Increasing behaviors of persons with severe retardation and autism by Richard M. Foxx

Toilet training persons with developmental disabilities: A rapid program for day and nighttime independent toileting by Richard M. Foxx

Functional behavior assessment for people with autism: Making Sense of seemingly senseless behavior by Beth A. Glasberg

Siblings of Children with Autism: A Guide for Families by Sandra L. Harris and Beth Glasberg

Autism through the lifespan – The Eden Model by David L. Holmes

Helping Your Child with Autism Spectrum Disorder: A Step-by-Step Workbook for Families by Jennifer M. Gillis , Stephanie B. Lockshin, and Raymond G. Romanczyk

A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism by Ron Leaf and John McEachin

A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know by Fred R. Volkmar and Lisa A. Wiesner

Activity Schedules for Children with Autism, Teaching Independent Behavior by Lynn E. McClannahan and Patricia J. Krantz

Teaching conversation to children with autism: Scripts and script fading by Lynn E. McClannahan and Patricia J. Krantz

Raising a child with autism: A guide to applied behavior analysis for parents by Shira Richman

Early Intervention Games: Fun, Joyful Ways to Develop Social and Motor Skills in Children with Autism Spectrum Disorder or Sensory Processing Disorders by Barbara Sher

Teaching language to children with autism or other developmental disabilities by Mark L. Sundberg and James W. Partington

Healthcare for children on the autism spectrum by Fred R. Volkmar and Lisa A. Wiesner

Reaching Out, Joining In: Teaching Social Skills to Children with Autism **by** Mary J. Weiss and Sandra L. Harris

Toilet training for individuals with autism and related disorders by Maria Wheeler

Internet Resources

Autism Society of America
http://www.autism-society.org/

A national organization of parents and professionals that promotes a better understanding

of autism, encourages the development of services, supports autism related research and advocates on behalf of people with autism and their families.

Autism Speaks
888-AUTISM2 (288-4762)
http://www.autismspeaks.org/

Autism Speaks was founded in by Bob and Suzanne Wright, grandparents of a child with autism. Autism Speaks is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Centers for Disease Control and Prevention (CDC)
Information in English and Spanish.
www.cdc.gov/ncbddd/autism/index.html

Provides parents, practitioners, teachers and others with credible data, statistics, diseases and conditions, populations, life stages environmental health, healthy living, injury, violence and safety.

Cure Autism Now (CAN)
http:// www.cureautismnow.org
http://www.canfoundation.org

A nonprofit organization dedicated to funding and promoting research with direct clinical implication for the treatment and cure of autism.

Disability Resources, Inc.
www.disabilityresources.org

An extensive collection of links that lead to information on many disabilities, including autism spectrum disorders, and to resources and support available in each state.

Exploring Autism Information in English and Spanish.
http://www. exploringautism.org/

A website that has been created to help families living with the challenges of autism to stay informed about the exciting breakthroughs surrounding the general information about the genetics of autism.

First Signs
http://www.firstsigns.org

A national non-profit organization dedicated to educating parents and professionals about the early warning signs of autism and related disorders.

Families for Early Autism Treatment (FEAT)
http://www.feat.org

A nonprofit network of organizations devoted to advocacy, education, and support of families and professionals.

Floortime Foundation
http://www.floortime.org

A website of Dr. Stanley Greenspan and his interventive program of Floortime based on his DIR (Developmental Individual-Difference Relationship-Based) model.

Lovaas Institute for Early Intervention
http://www.lovaas.com

An early intervention center promoting the UCLA Model of Applied Behavioral Analysis to teach children with autism in a comprehensive setting.

National Autism Center
1.877.313.3833
http://www.nationalautismcenter.org/index.php

It is a nonprofit organization that is dedicated to serving children and adolescents with Autism Spectrum Disorder (ASD) by providing reliable information, promoting the best practices, and offering comprehensive resources for families, practitioners, communities.

National Information Center for Children and Youth with Disabilities (NICHCY)
http://www.nichcy.org

An organization that can link parents to practically every government and nonprofit agency and organization involved in any way with disabilities.

Organization for Autism Research (OAR)
http://www.researchautism.org/

An organization that is led by parents and grandparents of children and adults on the autism spectrum. OAR uses applied science to answer questions that parents, families, individuals with autism, teachers and caregivers confront daily.

Untangle Autism
http://www.untaangleautism.org/iep.htm

An IEP center focusing on Individualized Education Plans for autistic individuals; helpful database provides a multitude of examples of IEPs.

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