CHAPTER-I

INTRODUCTION

WHAT IS DISABLITY?

Disability has been a universal human experience right from the inception. The term “disability” derive from a limitation in the functions and activities performed by individuals as members of society, thereby circumscribing their participation in the socio-cultural, political and economic life of their communities.

'Disability' is not a homogeneous category. It comprises different kinds of bodily variations, physical impairments, sensory difficulties or deficits, mental and learning deficiencies which may be either congenital or acquired. Authors have engaged with the term 'disability' in a variety of ways. It has been viewed as a marker of disease (ICD-10), of physical deficiencies, malformations and malfunctions (WHO, 2002), or alterations to kinship expectations and domestic duties (lngstad, 1995). Disability has been conceptualized in terms of circumscribed economic and productive roles (Stiker, 1999; Foucault, 1967) or in terms of community responses and obligations (Ingstad, 1995; Goffrnan, 1963).

As the term denotes a lack or deficiency, whether mental, physical or sensory, it has by and large been defined in medical terms. Yet, in all societies, the experience of disability is mediated by socio-cultural understandings that give meaning to impairments and affect the experiences of disabled people in various socio-historical contexts. Disability activists and scholars have long questioned exclusively medical definitions and have instead emphasized the social and cultural understandings that define power relations between the 'able' and disabled which result in the disabled being stigmatized and referred to the margins of social existence.

MENTAL HEALTH

Mental Health is a term used to describe either a level of cognitive or emotional well-being or an absence of a mental disorder. From perspectives of the discipline of positive psychology mental health may include an individual's ability to enjoy life and obtain a balance between life activities and efforts to achieve psychological flexibility.

The World Health Organization defines mental health as "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community Mental health can also be defined as an absence of a major mental health condition. Therefore the impact of social, cultural, physical and education can all affect someone's mental health.

History:

In the mid-19th century, William Sweetzer was the first to clearly define the term "mental hygiene", which can be seen as the precursor to contemporary approaches to work on promoting positive mental health.

Isaac Ray, one of thirteen founders of the American Psychiatric Association, further defined mental hygiene as an art to preserve the mind against incidents and influences which would inhibit or destroy its energy, quality or development.

At the beginning of the 20th century, Clifford Beers founded the National Committee for Mental Hygiene and opened the first outpatient mental health clinic in the United States.

AUTISM:

The term Autism Spectrum Disorder (ASD) constitutes a wide spectrum of neurodevelopment disorders described by impairment in several areas of development. The term ‘pervasive’ is used because many basic areas of psychological development are affected at the same time. The impairments are ‘qualitative’ and are distinctively deviant relative to the individual’s developmental or cognitive age.

These include difficulties in Social interaction, , communication social-emotional functioning, and unusual behaviours including stereotypic behaviours and/or restricted interests.

According to proposed revisions (DSM V Development) by American Psychiatric Association*, the term Autism Spectrum Disorder (ASD) includes autistic disorder (autism), Asperger’s Disorder, Childhood Disintegrative Disorder and PDD-Not Otherwise Specified (PDD-NOS).

Definition of Autism Spectrum Disorders (ASD)

Developmental disorders characterized by qualitative impairment in reciprocal social interactions along with qualitative impairment in communication and/or restrictive, repetitive and stereotyped pattern of behavior, interests and activities. In addition, children with ASD may have unusual responses to sensory experiences or perceptions.

Description of Disorders Included within ASD

□ *Autistic Disorder*

Autistic disorder is considered to be the behavioral model of Autism Spectrum Disorders, thus it will be discussed in depth here.

All of the following symptoms/deficits may/may not be present in a child. Since there is a wide variation in presentation of ASD, variable combination of symptoms may be present in a given child.

a. ***Deficits in reciprocal social interaction***

- This may manifest as a delay in appearance of social smile
- There may be impairment in the non-verbal behaviors used for social interaction (eye-to-eye contact, facial expressions, body postures and gestures)
- Child may appear to be “in his/her own world”
- There may be lack of spontaneous sharing of enjoyment and interests with other people
- Social interaction is rarely initiated naturally

- Contrary to popular belief, autistic children can show definite signs of attachment with familiar people or even clinginess to a specific caregiver.
- On the other extreme, these children may display excessive familiarity with strangers due to the absence of social inhibitions and stranger anxiety

b. ***Deficits in verbal and non-verbal communication***

- Approximately 50% never develop speech. In the remaining 50%, language acquisition is delayed and deviant
- This may manifest with impairment in the ability to initiate or sustain a conversation, or stereotyped, repetitive use of language
- Children may exhibit repetition of words or phrases regardless of meaning or relevance (echolalia) and pronominal reverse
- Delayed speech along with absence of meaningful gestures in children with autism results in significant handicap in terms of social communication. The child may not be able to understand gestures or use them during communication.
- There is delayed / absent proto declarative pointing or effort to indicate an item of interest to another person
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c. ***Stereotypic Behavior***

- Restrictive and repetitive behaviors present as stereotypic movements (body rocking, finger twirling, hand flapping, spinning and tiptoe walking)
- A preoccupation with certain ideas or objects (i.e. a fascination with certain numbers, letters, schedules, animate or inanimate objects especially parts of a toy)
- An apparently inflexible adherence to specific, nonfunctional routines or rituals
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d. ***Sensory Deviance***

- These may be visual (seeing things from a particular angle), auditory (appearing deaf at times, clapping hand over their ears), olfactory (sniffing objects) or perceptual (refusing to eat food with certain textures or tastes, mouthing of objects, compulsive touching of certain objects or textures, diminished response to pain)

- Increased sensitivity to touch, including but not limited to the feel of running water, adversity to bathing

e. *Play*

- This may be atypical or deviant, and if present, is mechanical and repetitive
- Imaginative play is markedly impaired or absent
- The child may play with objects which are not usually used for play by children of the same developmental level. E.g. A six-year old child collecting and playing with shoes, papers or wrappers
- Lining things up

f. *Abnormalities of mood or affect*

- Mood may be inappropriate to the situation or circumstances.
- This may be in the form of uncontrollable crying or laughing in a situation where it is not warranted.

Autism is defined by the **Autism Society Of America (ASA)** as: "Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism was also known as 'childhood schizophrenia', a misleading term, as, unlike schizophrenics, autistic individuals did not appear to have hallucinations or delusions. Kanner believed that autism was an innate disorder present since birth; unlike schizophrenics, autistic children did not 'withdraw' from the world; rather, they were unable to participate in it, in the first place.

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by “severe and pervasive impairment in several areas of development."

Autism occurs in as many as one or two per 1,000 children. It is found four times more often in boys (usually the first-born) and occurs around the world in all races and social backgrounds. Autism usually is evident in the first three years of life, although in some children it's hard to tell when the problem develops. Sometimes the condition isn't diagnosed until the child enters school.

While a person with autism can have symptoms ranging from mild to severe, about 10% have an extraordinary ability in one area, such as in mathematics, memory, music, or art. Such children are known as "autistic savants" (formerly known as "idiot savants.").

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colors.

THE CONCEPTS WHICH ARE COMMONLY PREVAILING IN THE SOCIETY

Autism is a brain disorder that affects the way the brain uses or transmits information. Some of the Case Studies have found abnormalities in several parts of the brain that almost certainly occurred during fetal development. The problem may be centered in the parts of the brain responsible for processing language and information from the senses.

There appears to be a strong genetic basis for autism. Identical twins are more likely to both be affected than twins who are fraternal (not genetically identical). In a family with one autistic child, the chance of having another child with autism is about 1 in 20, much higher than in the normal population. Sometimes, relatives of an autistic child have mild behavior that look very much like autism, such as repetitive behaviors and social or communication problems. Research also has found that some emotional disorders (such as manic depression) occur more often in families of a child with autism.

At least one group of researchers has found a link between an abnormal gene and autism. The gene may be just one of at least three to five genes that interact in some way to cause the condition. Scientists suspect that a faulty gene or genes might make a person vulnerable to develop autism in the presence of other factors, such as a chemical imbalance, viruses or chemicals, or a lack of oxygen at birth.

In a few cases, autistic behavior is caused by a disease such as:

- rubella in the pregnant mother
- tuberous sclerosis
- fragile X syndrome
- encephalitis

The severity of the condition varies between individuals, ranging from the most severe (extremely unusual, repetitive, self-injurious, and aggressive behavior) to very mild, resembling a personality disorder with some learning disability.

Profound problems with social interaction are the most common symptoms of autism. Infants with the disorder won't cuddle; they avoid eye contact and don't seem to want or need physical contact or affection. They may become rigid or flaccid when they are held, cry when picked up, and show little interest in human contact. Such a child doesn't smile or lift his arms in anticipation of being picked up. He forms no attachment to parents nor shows any normal anxiety toward strangers. He doesn't learn typical games of childhood, such as peek-a-boo.

HOW ONE CAN EDUCATE SOCIAL SKILLS IN YOUNG CHILDREN:

Social Skills are the prominent part in the child’s development how they inculcate their intellectual and built their mental health it can be depends up on three major areas: If the child face difficulty than it can leads towards pathological condition among children:

The main three areas of difficulty

It has always been recognized that social interaction is an area of difficulty for children diagnosed with an ASD but in the seventies Dr Lorna Wing and Dr Judith Gould defined the key areas by introducing the triad of impairments:

- **Social Interaction** (difficulty with social relationships, for example appearing aloof and indifferent to other people)
- **Social Communication** (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice)
- **Social Imagination** (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively).

It is not that children with an ASD will never be able to learn these skills, but more that they are going to need specific teaching in these areas. Most children learn social skills by watching their peers, experimenting in imitation , by observing their elders and siblings and refining their skills as they go. Children with an ASD can find this difficult so they seem to miss many opportunities to practice these skills. Social skills and social situations need to be broken down, explained, and practiced so children with an ASD can absorb them at a level that makes sense to them. A young woman with Asperger syndrome explained:

It would be an understatement to say that a wide range of hypotheses are used to account for autism-related disorders. Historically, the disorders have been understood mainly through psychoanalytical, neurobiological, genetic and executive function approaches. There have, however, also been combinations of unrelated approaches.

Historical definition of autism

Bleuler defined the concept of autism in 1911, believing it was not a separate condition but one of the secondary effects of schizophrenia.

Thirty-two years later, in 1943, Leo Kanner described autism as a rare psychiatric disorder with onset before age two-and-a-half years of age. Kanner’s definition and his subsequent description of its main distinguishing characteristics made autism a medical entity (Kozloff, 1998). As a new psychiatric medical entity, the practitioners of the day offered as treatment psychoanalytic forms of therapy.

By the late 1950s, current thinking about autism was changing. In 1959, for example, Bender characterized autism not as an inborn impairment of the central nervous system, but as a defensive reaction to one—a disorder whose basis is an inability to shield self from unbearable anxiety. A year later, C.E. Benda wrote that the autistic child is “not mentally retarded in the ordinary sense of the word, but rather is a child with an inadequate form of mutation which manifests itself in the inability to handle symbolic forms and assume an abstract attitude.”

During the mid-1960s, understanding of autism continued to shift. In 1964 Bernard Rimland published a biogenic theory of autism: “The basis of the autism syndrome is the child’s impaired ability to relate new stimuli to remembered experience. Hence, the child does not use speech to communicate because he cannot symbolize or abstract from concrete particulars. And he is unresponsive to his parents because he does not associate them with previous pleasurable experiences.” Rimland thought that the underlying cause of autism was impairment in the brain’s reticular formation—the part of the brain felt by many to link sensory input and prior content.

During the 1960s and into the 1970s researchers offered biogenic explanations of autism—theories focusing on biochemical and metabolic anomalies in people with autism, or on the role in the development of autism of various problems of the central nervous system. Autism was beginning to be viewed as a neurological disorder.

This viewpoint is still very much with us. Speaking at the 1999 National Conference of Autism, James Ball referred to autism as a complex developmental disability resulting from a neurological disorder that affects the functioning of the brain.

That year, clinical practice guidelines on autism published by New York State referred to it as a part of a clinical spectrum of pervasive developmental disorders.

“Autism is a neurobehavioral syndrome caused by dysfunction in the central nervous system, which leads to disordered development.”

Beginning in the mid-1960s and carrying forward through the 1980s to 2000, researchers have turned to genetics, searching for the genetic error, perhaps inherited, and underlying the development of autism. The roles of several candidate genes are being studied.

In the 1990s, other approaches to autism were described, including the executive functions approach, the hypothesis that autism results from early life brain damage, the theory that autism is the result of neuro-immune dysfunction, and that it is the result of autistic enter ocolotitis, which may be linked with the measles, mumps and rubella vaccination.

HOW TO DEAL WITH AUTISM IN ITS REAL SENSE:

Addressing behavioral challenges for individuals with ASD Effective teaching strategies for students with autism require development of a systematic program for addressing problem behaviors. Students with autism often exhibit a wide variety of challenging behaviors, including physical aggression, self-injury, tantrums and non-compliance. These behaviors are disconcerting to staff and parents, and should be resolved. Developing effective behavior intervention programs is often the most important step for the classroom or home. The following are important elements of an effective program:

The gist of the functional assessment can be put like this

- Developing and writing a behavior intervention plan
- Identifying the principles of active programming
- Teaching replacement skills
- Reviewing environmental controls
- Implementing compliance training
- Planning reactive programming
- Developing a crisis management plan

An effective program for managing problem behaviors focuses on two main strategies: proactive programming and reactive programming

Principles of proactive programming

Highly effective programs for students with autism emphasize proactive strategies for reducing problem behaviors and teaching replacement skills. Proactive programs:

- Assume the problem behavior serves a purpose for the student and attempts to teach alternative and replacement skills that serve the same function
- Modify the antecedents and environmental controls
- Begin by determining the function of the maladaptive behavior for the student
- Seek replacement behaviors for the maladaptive behavior

Principles of reactive programs

Systematic reactive programs can effectively decrease the frequency and duration of problem behaviors. Unfortunately, most classrooms for students with autism focus entirely on reactive programming to analyses the child's behavior.

Reactive programs: Wait for the maladaptive behavior to occur and then respond with a punishment

- Focus on the consequences of the behavior
- May ultimately reinforce the maladaptive behavior
- Do not significantly or permanently change maladaptive behaviors

Functional assessment

A comprehensive intervention program for students with autism will provide a careful balance between both a proactive and reactive program. This involves conducting a thorough functional assessment and developing an appropriate behavior intervention plan.

A thorough functional assessment is the first step in a proactive program. It begins the process of understanding the purpose of the student's behavior and what the student is trying to communicate. The goal of a functional assessment is to identify the purpose and effect of a target behavior by examining its function for the student.

An effective functional assessment is built on several assumptions and presumptions:

- That the problem behavior serves a function for the student. A student exhibiting problem behaviors is using a functional approach to communication to achieve a specific outcome. Therefore, school personnel must conduct a functional assessment to thoroughly understand function of the behavior for the student.
- That if a student is repeating a problem behavior, then the consequence of the behavior has been reinforced for that student in the past. Each of us tends to repeat behaviors that are positively reinforced.
- That a student exhibiting problem behaviors often does not know the correct adaptive skills or has not been reinforced effectively for displaying appropriate adaptive behaviors.

Functional assessment made easy

Whether mandated through an IEP team or conducted as an informal assessment by the classroom staff, a functional assessment can be conducted efficiently and easily with the right tools.

Step 1: ANALYSIS OF BEHAVIOUR:

Firstly, detail description towards an observable and measurable target behavior. The problem behavior targeted for a functional assessment will vary with the student. The team may choose to target a behavior which can be easily corrected before moving to more challenging behaviors. Targeting lesser behaviors may build success for the student and staff and make changing more challenging behaviors easier.

If, however, behaviors are harmful to the student or others, the team may choose to work on several behaviors at once. All identified target behaviors must be clearly defined and measurable to ensure consistency across settings.

Step 2: COLLECTION OF RELEVANT INFORMATIONS:

Collect information from a variety of sources. The team may interview teachers, parents and related service personnel who work with the student. Interview data focuses on the antecedents and consequences of the behavior. Interview adults who have a significant relationship with the student and who can contribute to defining the target behavior and function.

Direct observation is the best method to collect the right information about child’s behavior.. Observations focus on the frequency, duration and intensity of the target behavior. Observations should occur in the natural settings where the target behavior is exhibited. Direct observations also include an analysis of environmental factors that may contribute to the maladaptive behavior.

Physiological factors are the last area of data collection which may influence problem behaviors. Students with autism often have potential medical issues that are causing an increase in maladaptive behaviors. Physiological areas to be considered in a functional assessment include:

- Diet and nutrition
- Sleep patterns and fatigue

- Medication side effects
- Sickness
- Stress outside the classroom

It is important to carefully consider how these variables influence problem behaviors. If the student is hungry or thirsty and has no functional communication system, the outcome will be irritability and an increase in problem behaviors. The classroom team can effectively address these issues and reduce further problem behaviors.

Step 3: BEHAVIOURAL INTERVENTION PLAN:

The behavioral intervention plan is a written and descriptive document that includes:

- An operational definition of the target behavior.
- Summary of the relevant data.
- Written hypothesis statement stating the function of the behavior.
- List of modifications to the environment.
- Teaching replacement or alternative behaviors.
- Criteria or outcome evaluation.
- Consequence strategies: crisis intervention plan and reactive programming.

Most school districts have developed appropriate forms to be used for a written behavior intervention plan. If no form is readily available, the teacher can easily create an individualized plan for use in the classroom.

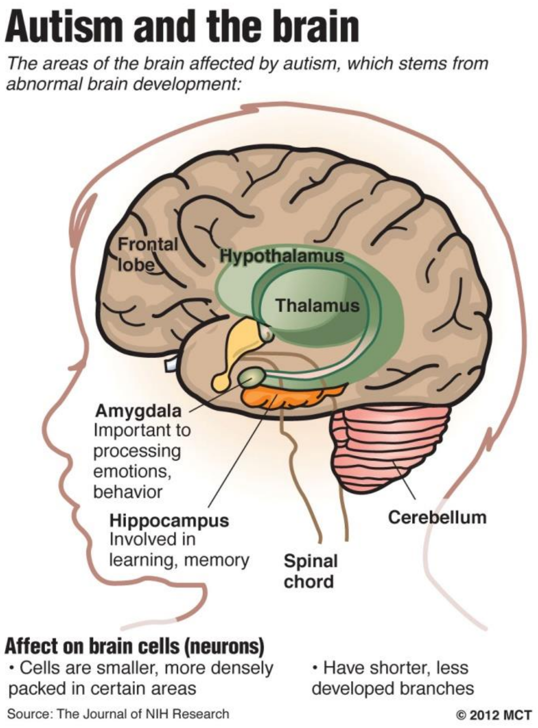
The behavior intervention plan requires two main components: teaching replacement skills and modifying the environment. Teaching replacement skills or alternative behaviors assumes that the student's problem behavior is meeting a need for the student and that the student may not have the skills required for more adaptive behaviors. The replacement behavior, therefore, must be as effective and powerful as the maladaptive behavior.

For example, if Zachary receives immediate and intense attention from the teacher for biting another student, the new replacement behavior must also give Zachary the same immediate and intense attention from the teacher. Teaching Zachary to raise his hand and wait several moments for the teacher's attention will not be an effective alternative skill.

The major key concept: teaching replacement skills—teaching the desired replacement skill should result in:

- Meeting the same function or purpose for the student
- Teaching a skill that can be implemented across settings
- An efficient and effective alternative for the student

Teaching replacement behaviors to students with autism uses a variety of instructional techniques. While discrete trial instruction and incidental teaching are highly effective strategies in teaching replacement behaviors, the classroom staff can also implement other techniques including shaping, differential reinforcement and token economies.



Autism and the brain

The areas of the brain affected by autism, which stems from abnormal brain development:

Affect on brain cells (neurons)

• Cells are smaller, more densely packed in certain areas

• Have shorter, less developed branches

Source: The Journal of NIH Research

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CAUSES AND FACTORS FOR AUTISM:

Autism can result from any factor that hinders healthy brain development. In many cases, doctors cannot identify any single cause for the condition. Factors involved in autism fall into the broad categories of:

(1) Genetic and

(2) Environmental.

Genetic Factors:-

Genetic factors involve faulty chemical instructions in genes, the hereditary material in every cell. In human cells, genes are carried on 46 microscopic threads called chromosomes that are arranged in 23 pairs. Scientists have made great progress in learning how genes function. Some genetic errors cause mental retardation. In some cases, such errors are inherited. Others occur spontaneously for unknown reasons.

One common genetic cause of retardation is a disorder called Down syndrome, in which people have an entire extra chromosome, for a total of 47. Another common genetic factor is called fragile-X syndrome. This condition involves an abnormality in the X chromosome, one of the chromosomes that determines a person's sex.

Many less common genetic factors affect genes that control a particular chemical pathway in the body. One such condition is phenylketonuria, often abbreviated PKU. People with PKU cannot process one of the subunits called amino acids in proteins. This amino acid builds up and leads to mental disorder if their diet is not controlled.

Environmental Factors:-

Environmental factors include a wide variety of influences that can affect brain development before, during, or after birth. During pregnancy, a woman's general health and nutrition greatly affect her unborn baby. Consumption of alcohol during pregnancy can lead to a condition in the baby called fetal alcohol syndrome. This syndrome causes many serious health problems, including mental retardation. Use of prescription, nonprescription, or illegal drugs can also harm a developing baby's brain. Exposure before birth to certain infections, including rubella (also called German measles) and HIV, can also cause autism.

Events at birth can also harm the brain. Premature birth, injury during delivery, and failure of the newborn to breathe properly can all lead to retardation. During childhood, autism can result from such causes as brain infections, head injuries, prolonged high fevers, or lead poisoning.

Understanding autism

Autism is a disorder that appears in early childhood, causing delays in many basic areas of development such as learning to talk and interact with others. The symptoms of autism vary widely, as does the impact of the disorder: some autistic children have only mild impairments, while others have more obstacles to overcome. But although the specific combination of symptoms and the severity of the disorder differ from person to person, kids with autism typically have problems in the following three areas:

- **Social Skills** — Impaired social interaction is the hallmark sign of autism. This may appear as an apparent lack of interest in other people and the surrounding environment. Children with autism often appear to be in their own little world. They have trouble engaging in back-and-forth play, sharing emotions, making friends, and understanding what others are thinking and feeling.

- **Communication** — Autism also involves problems with verbal and nonverbal communication. Spoken language is usually delayed in autistic children and may even be completely absent. Even when able to speak, children with autism usually have trouble conversing freely and easily. Other common symptoms involve odd or repetitive speech patterns, inappropriate facial expressions and gestures, and language comprehension difficulties.

- **Repetitive behavior** — Autistic children often exhibit repetitive or "stereotyped" behaviors and narrow, restricted interests. This may show up as an extreme resistance to change, obsessive attachments to unusual objects, or inflexible routines and schedules. Repetitive body movements, or *self-stimulatory behaviors*, such as hand flapping and rocking are also common.

There is some debate over how many people have autism and whether or not the disorder is becoming more prevalent. While more children are being diagnosed with autism than in the past, many experts believe that at least some of the increase can be explained by heightened public awareness of the disorder, as well as broader and more accurate diagnostic criteria that is catching milder cases.

On the other hand, the latest research indicates that—at the very least—autism is more common in the U.S. than previously thought. According to a February 2007 report from the Centers for Disease Control and Prevention (CDC), 1 in 150 children has autism.

While autism occurs with equal frequency across all races, ethnicities, and social classes, boys are three to four times more likely to have autism than girls. The siblings of those with the disorder are also at a higher risk.

VARIOUS TYPES/FORMS OF AUTISM:

These are the most common disorders, all presenting in a somewhat similar manner, but having slight variations:

***Autistic Disorder* -** As stated above, and defined by the Autism Society of America (ASA): "Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by “severe and pervasive impairment in several areas of development."

Pervasive Developmental Disorder **(P.D.D)** - Also called "Atypical Autism." Children with this disorder have many of the same characteristics of Autism, but not all the criteria associated with Autism.

Asperger's Disorder - Children with this disorder do not have the usual language barriers associated with Autism and are generally very intelligent. However, they do tend to struggle with social interactions, and can possess on a particular object or subject they take an interest in, and talk about it constantly

Retts Disorder - Retts is rather similar to Autism, but presents only in girls. The children begin to develop on target, but then begin losing some communication abilities. The symptoms of Retts can begin to occur between ages 1 and 4.

THE PREVAILING POSITION OF AUTISM IN INDIA

Recent estimates have placed the prevalence of autism in the U.S. at approximately 1 in 150 people. At India’s current population, this means there are more than 2 million autistic persons in the country. Of course, this estimate assumes that there are no significant variations in this rate worldwide, which is a question that has not yet been addressed by epidemiologists outside the West. While the disorder is not rare, the majority of autistic people in India have not been diagnosed and do not receive the services they need. This problem occurs in many countries, but is especially true in India where there is a tremendous lack of awareness and misunderstanding about autism among the medical professionals, who may either misdiagnose or under diagnose the condition.

One of the major difficulties faced by parents of children with autism in India is obtaining an accurate diagnosis. A parent may take their child to a pediatrician only to be reassured that their child is just "slow." Unsatisfied, they may visit a psychologist, to be told their child is "mentally subnormal." Convinced that their child does not fit the typical picture of mental retardation, they may visit a psychiatrist, to be told that their child has attention deficit disorder, and must be put on medication to control hyperactivity. After months of sedation and unsatisfactory progress, they may again begin a cycle of searching for the correct name for their child’s problem. Some doctors may feel that nothing can be gained by a diagnosis of autism if the services are not there; yet, as more children are diagnosed as autistic and more awareness of the disorder spreads, there will be a demand for services. Schools will be forced to educate themselves if they find that more of the population they serve is autistic.

Admittedly, there are not enough services to meet the needs of mentally retarded children and adults in India, they are not given much attention in our society. Let them alone those who are autistic. Let this then be an impetus to create more, and ensure that the special needs of autistic children are not ignored. They have also equal right to live, survive. There is also an urgent need to begin planning homes and centers for these children when they become adults: people with autism have a normal life span and many will require supervision after their parents' death. Currently, the needs of autistic children in India are not being met in either the regular or special education systems. With an understanding teacher or possibly an aide, a more able autistic child could function very well in a regular school, and learn valuable social skills from his peers. However, even children with very high I.Q.'s are often not permitted in regular classes. Also, the rigidity and pressure of schools in India can make it difficult for an autistic child to cope without special allowances. Some middle and lower functioning children, who form the majority of autistic children, may attend special schools, but these schools almost always lack an understanding of effective methods of handling the challenging behaviors of autistic children. As one psychologist noted, "The kids just get 'dumped' or ignored at the special schools." Children with autism are frequently refused admission in these special schools because officials protest they are not equipped to handle autistic children, who are sometimes more challenging than children with mental retardation alone. We believe that special schools should invest in learning these techniques, rather than turning parents away!

Primarily as a result of intense work by AFA with the Ministry of Health in the mid-1990's, the Government of India now recognizes autism as a disability. This development is relatively recent: formerly, schools catering solely to autistic persons were not able to receive funding from the government. Persons with autism were also not eligible for concessions and benefits offered by the government unless they were diagnosed as mentally retarded, yet many persons with autism are *not* mentally retarded. Through the commitment of a community of parents, siblings, other relatives, and autistic people themselves, people with autism and their families now have a voice in the disability legislation and movement in India. While we are pleased that autism now receives recognition, there are still many issues to be negotiated, legal and otherwise. Parents should continue to educate themselves about the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, to be aware of what are their rights and benefits are as caregivers of autistic children.

HOW GENDER RELATED TO AUTISM:

In today's scenario recent, questions have been come up about the ratio of males to females diagnosed as having an autism spectrum disorder (ASD). Overall the most recent studies suggest that the prevalence of autism spectrum disorder is about one in 100, but what of the male/female ratio?

There is no hard evidence of numbers. Various studies, together with subjective evidence, have come up with male/female ratios ranging from 2:1 to 16:1. Whatever the true ratio, clinical referrals to a specialist diagnostic center such as The National Autistic Society's Lorna Wing Centre have seen a steady increase in the number of girls and women referred. Because of the male gender bias, girls are less likely to be identified with ASD, even when their symptoms are equally severe. Many girls are never referred for diagnosis and are missed from the statistics. At The Lorna Wing Centre, emphasis is placed on the different manifestations of behaviour in autism spectrum conditions as seen in girls and women compared with boys and men.

In one of the study the Researcher has identified the different way in which girls and women present under the following headings; social understanding, social communication, social imagination which is highly associated with routines, rituals and special interests. Some examples cited in the paper are:

- Girls are more able to follow social actions by delayed imitation because they observe other children and copy them, perhaps masking the symptoms of Asperger syndrome (Attwood, 2007).

- Girls are often more aware of and feel a need to interact socially. They are involved in social play, but are often led by their peers rather than initiating social contact. Girls are more socially inclined and many have one special friend.

- In our society, girls are expected to be social in their communication. Girls on the spectrum do not 'do social chit chat' or make 'meaningless' comments in order to facilitate social communication. The idea of a social hierarchy and how one communicates with people of different status can be problematic and get girls into trouble with teachers.

- Evidence suggests that girls have better imagination and more pretend play (Knickmeyer et al, 2008). Many have a very rich and elaborate fantasy world with imaginary friends. Girls escape into fiction, and some live in another world with, for example, fairies and witches.

- The interests of girls in the spectrum are very often similar to those of other girls – animals, horses, classical literature – and therefore are not seen as unusual. It is not the special interests that differentiate them from their peers but it is the quality and intensity of these interests. Many obsessively watch soap operas and have an intense interest in celebrities.

The presence of repetitive behavior and special interests is part of the diagnostic criteria for an autism spectrum disorder. This is a crucial area in which the male stereotype of autism has clouded the issue in diagnosing girls and women.

As highlighted above, the current international diagnostic criteria do not give examples of the types of difficulties experienced by girls and women. In order to recognize the different behavioral manifestations, it is important to take a much wider perspective regarding the social, communication and imagination dimensions in addition to the special interests and rigidity of behavior. The girls and women learn to act in social settings. Unenlightened diagnosticians perceive someone who appears able and who has reciprocal conversation and who uses appropriate affect and gestures as not fulfilling the criteria set out in the international classification systems. Therefore a diagnosis is missed. It is only by asking the right questions, taking a developmental history, and observing the person in different settings, that it becomes clear that the individual has adopted a social role which is based on intellect rather than social intuition. To quote: "The fact that girls with undiagnosed autism are painstakingly copying some behaviour is not picked up and therefore any social and communication problems they may be having are also overlooked. This sort of mimicking and repressing their autistic behavior is exhausting, perhaps resulting in the high statistics of women with mental health problems."

THE CAUSES FOR ITS RISE DAY BY DAY

Autism is clearly an epidemic. According to the Center for Disease Control (CDC), the prevalence of autism is now 1 in 166 children. Prior to the mid-1980s, the rate of autism was estimated to be 1 in 2,000 children, a 1,200% increase! The big question: What is responsible for the dramatic increase in autism over the past 20 years?

Some people argue that the increase in autism reflects better ways to diagnose these children and an increase in awareness of the disorder. Many of them also claim that the underlying cause of autism is purely genetic. There are problems with these claims:

- There can be no epidemic of purely genetic diseases. The prevalence of genetic diseases is expected to increase only about 1% per century.

- Prior to the mid-1980s, two-thirds of the children diagnosed with autism were affected at birth (i.e., early onset), and only one-third became autistic between their first and second year of life (i.e., late onset). Today, the opposite is true. One-third have early onset autism and two-thirds have late onset autism. The notions that the increase in autism is due to better diagnosis and/or awareness and/or is genetic does not explain the huge increase in late onset autism.

- If autism has always been highly prevalent, where are the 1 in 166 autistic adults? There are still only a relatively small number of autistic adults, even though their numbers will increase enormously in the coming years.

  There are many theories on why the prevalence of autism has increased over the past 20 years, including a yet-to-be identified virus. One thing is for certain: there is growing scientific evidence linking vaccines with autism. There are two aspects to the vaccine issue. One is the mercury problem. Mercury is highly neurotoxin and is used as a preservative, called thimerosal, in many vaccines. Second is the Measles-Mumps-Rubella (MMR) vaccine. Here are just a few of the arguments in support of the autism–vaccine connection:

Research has shown that many autistic children have very high levels of mercury and other heavy metals in their bodies. Additionally, according to a survey by the Autism Research Institute, parents rated chelation, a method to detoxify the body from heavy metals, as the single most effective biomedical intervention that they have tried on their children, of the 80 biomedical interventions (including 45 drugs), they were asked to rate.

Some critics argue that since mercury (or thimerosal) has been removed or reduced in vaccines, one should expect a decrease in the rate of autism. In 1999, the Food and Drug Administration (FDA) asked (not demanded) the drug manufacturers to remove mercury from the vaccines. We assume drug manufacturers started to comply with this request in 1999/2000 and that the mercury containing vaccines are still being phased out. Since the average age of diagnosis of autism is four years, one would expect to see a decrease in autism in 2004. The California Department of Developmental Disabilities Service has been keeping careful track of the incidence of autism over the years, and there is some indication that the rate of autism in 2004 is starting to decrease.

Soon after the MMR vaccine was introduced in the U.S., the rate of autism began to rise. The MMR vaccine was introduced in the United Kingdom about 10 years later, and the incidence of autism, again, soon began to rise. Note: some people claim that the increase in autism in the U.K. occurred several years prior to the introduction of the MMR. However, these critics do not take into account the “catch-up” period in which older children were also given the MMR vaccine.

A series of studies by Dr. Andrew Wakefield, as well as several other scientists worldwide, have found live measles virus in many children who became autistic after receiving the MMR (i.e., late-onset autism).

We must rely on science to determine the true cause(s) of autism. At this point, scientific studies are providing some evidence suggesting that vaccines may be associated with autism.

HOW THERE CAN BE GOOD PARENTING WITH AN AUTISTIC CHILD:

Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Parents raising a child with autism face extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life (Dyches et al 2004).There are high-risk factors that might induce acute or chronic stress and trauma to the parents of autistic children and, in turn, lead to dysfunctional parenting. These include: a) theambiguity of diagnosis; b) the severity and duration of the child’s disorder; c) a very low I.Q.; d)lack of congruity with the community norms, bizarre forms of communication and behavior; and,e) enduring disruptive or disorganized behaviors(Kourkoutas et al 2012).Families with autistic children have been perceived by their societies in different ways causing the families to be shaped by the beliefs systems of autism specific to their society. Because of social stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness. Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals and receive a diagnosis for their children.

To be diagnosed to autism , families can avoid having disability identities (Ecker 2010). The troublesome symptoms such as tantrums, self-destructive acts and other inappropriate public behaviours associated with the disorder are difficult to cope with. Consequently, the parents with autistic children frequently encounter hostile or insensitive reactions from public, mostly because of the inappropriate behaviour shown by their children. The public reaction to such families is often stereotypical and negative (Gray 1993). Because of delayed communication in autistic children, parents may experience positive and negative changes as the children grows and enters school system. The school system initiates a new involvement concerning the needs of the child and the parent. Parents and school personnel are closely related in pursuing the most appropriate education for the child (Hoppe 2005). Caregivers of autistic children may perceive their children as more difficult temperamentally than other children and therefore, use greater control strategies with their children. Thus, caregiver perceptions of their children's characteristics may influence the ways in which they interact with their children (Kesari et al 1997).The family social support from relatives, neighbors and friends relatives, neighbors, friends plays a vital role to release and coping the stress and anxiety due to having a child with developmental disabilities.

Problems which are faced by Autistic Children in their routine lives:

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

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

First, this disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, and blindness. Without a definitive test, the diagnosis of and prognosis for autism is fraught with uncertainty. This ambiguity makes it extremely difficult for parents to accept the child’s condition and second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood Autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children than parents of children with other physical or learning disabilities or parents with children with other developmental disabilities (Budzienski, 2014). Characteristics that are common among children with autism and contribute to parenting stress include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors. The deficit in emotional expressiveness of autistic children may lower empathy between mother and child, and thus induce greater parental stress. Existing studies of families of children with autism suggest that behavioral, social, and cognitive dimensions of the disorder are associated with stress in parents. It is true, that the more severe the child's symptoms, the greater will be the degree of parental stress. Furthermore, the more the negative characteristics a child has, the more socially isolated the family will be and more the feelings of stigmatization that they will experience (Pathappili, 2011). Gray conducted a study in 2003 found that almost all parents with children with autism have felt stigmatized in public situations for example at the supermarket or a shopping mall), and that parents of younger and/or more severely disabled children felt more stigmatized.

Other important factors associated with parental stress in families of children with autism, include, feelings loss of personal control, absence of spousal support, informal and professional support. Research further suggests that parents of autistic children are likely to encounter increased risks of experiencing persistent feelings of distress and sorrow. the uncertainty generated by the unpredictability of their child's future quality of life, and stress related to the child's lack of ability to communicate or to his incomprehensible and bizarre behavior, may hinder the development of adequate parenting practices (Ebata et al). Parents also feel overwhelmed by the challenges of achieving the social inclusion of their child both at school and in the community.

Gray 1993 found in a study that many parents have reported positive experiences about rearing a child with autism. They find greater meaning in their own lives, and being delighted with their child's accomplishments , Despite these positive reports substantial research evidences indicates that the parents of children with autism , especially mothers , experience greater amounts of stress and depression than do the parents of children who are developing in typical ways or who have other types of developmental disorder. The first challenge parents of children with ASD face is the diagnosis itself, which can bring heartbreak, anxiety, anger and a feeling that life has been unfair. Another hurdle for parents is the strain having a child with such extensive needs places on the family unit. Mother can play a positive role in the overall development of an autistic child hence they suffer from developmental disability and other many areas required for caring and nurturing to their children with autism.

According to Autism Society they highlighted that siblings feel overshadowed by the needs of the child with autism, and while some are able to form a close relationship, others may grieve the loss of a typical playmate. But there is certainly hope in this realm. It is important to remember that while having a sibling with autism or any other disability is a challenge to a child, it is not an insurmountable obstacle. Most children handle the challenge effectively, and many of them respond with love, grace, and humor far beyond their years." Many parents of autistic children also report feeling a lack of support. A study published in the journal Qualitative Health Research in 2008 by Sauna, found that a common feeling which is found in majority of families are extreme social isolation and a lack of understanding about the disorder. Sometimes the difficulties of autism can lead to behaviors that are quite challenging for us to understand and address. Autism Speaks recommends that parents consult with their child's team -- usually consisting of special education teachers, the occupational therapist, the speech-language pathologist, the behavioral therapist and other professionals who may provide direct services -- to help them create a consistent plan for dealing with challenging behaviors in and out of school. Parents also faced heavy financial demands of having a child with autism.

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

Problems with language:

The child with autism may not speak at all; if he does, it is often in single words. He may endlessly repeat words or phrases that are addressed to him and may reverse pronouns ("You go sleep" instead of "I want to go to sleep").

Less interests and activity :

Usually a child with autism has many problems playing normally. He/she probably won't act out adult roles during play time, and instead of enjoying fantasy play, he/she may simply repeatedly mimic the actions of someone else. Bizarre behavior patterns are very common among autistic children and may include complex rituals, screaming fits, rhythmic rocking, arm flapping, finger twiddling, and crying without tears. Autistic children may play with their own saliva, feces or urine. They may be self-destructive, biting their own hands, gouging at their eyes, pulling their hair, or banging their head.

Sensory problems

The sensory world poses a real problem to many autistic children, who seem overwhelmed by their own senses. A child with autism may ignore objects or

become obsessed with them, continually watching the object or the movement of his fingers over it. Many of these children may react to sounds by banging their head or flapping fingers. Some high-functioning autistic adults who have written books about their childhood experiences report that sounds were often excruciatingly painful to them, forcing them to withdraw from their environment or try to cope by withdrawing into their own world of sensation and movement.

Intellectual level problems

Most autistic children appear to be moderately mentally retarded. They may giggle or cry for no reason, have no fear of real danger, but exhibit terror of harmless objects.

— Carol A. Turkington

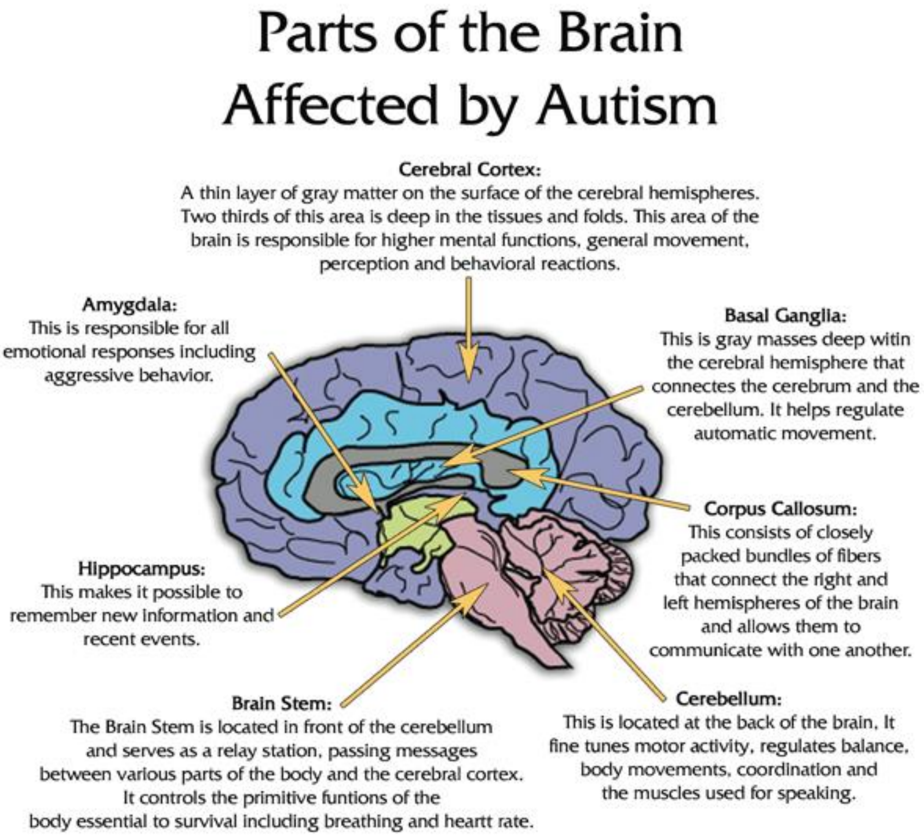
There is no medical test for autism. Because the symptoms of autism are so varied, the condition may go undiagnosed for some time (especially in those with mild cases or if other handicaps are also present). It may be confused with other diseases, such as fragile X syndrome, tuberous sclerosis, and untreated phenylketonuria.

Autism is diagnosed by observing the child's behavior, communication skills, and social interactions. Medical tests should rule out other possible causes of autistic symptoms.

Following Criteria that mental health experts and pathologist can use to diagnose autism include:

- problems with developing friendships
- problems with make-believe or social play
- endlessly repeated words or strings of words
- difficulty in carrying on a conversation
- obsessions with rituals or restricted patterns
- preoccupation with parts of objects

Below figure shows the various parts of the brain which are affected by Autism.



Parts of the Brain Affected by Autism

Cerebral Cortex: A thin layer of gray matter on the surface of the cerebral hemispheres. Two thirds of this area is deep in the tissues and folds. This area of the brain is responsible for higher mental functions, general movement, perception and behavioral reactions.

Amygdala: This is responsible for all emotional responses including aggressive behavior.

Basal Ganglia: This is gray masses deep witin the cerebral hemisphere that connectes the cerebrum and the cerebellum. It helps regulate automatic movement.

Corpus Callosum: This consists of closely packed bundles of fibers that connect the right and left hemispheres of the brain and allows them to communicate with one another.

Hippocampus: This makes it possible to remember new information and recent events.

Brain Stem: The Brain Stem is located in front of the cerebellum and serves as a relay station, passing messages between various parts of the body and the cerebral cortex. It controls the primitive funtions of the body essential to survival including breathing and heartt rate.

Cerebellum: This is located at the back of the brain. It fine tunes motor activity, regulates balance, body movements, coordination and the muscles used for speaking.

Some children have a few of the symptoms of autism, but not enough to be diagnosed with the "classical" form of the condition. Children who have autistic behavior but no problems with language may be diagnosed with "Asperger syndrome." Children who seem normal at first but who begin to show autistic behavior as they get older might be diagnosed with "childhood disintegrative disorder" (CDD). These problems are sometimes called "autistic spectrum disorders." It is also important to rule out other problems that seem similar to autism.

There is no cure for autism. Treatments are aimed at reducing specific symptoms. Because the symptoms vary so widely from one person to the next, there is not a single approach that works for every person. A spectrum of interventions include training in music, listening, vision, speech and language, and senses. Special diets and medications may also be prescribed.

Studies show that people with autism can improve significantly with proper treatment. A child with autism can learn best with special teachers in a structured program that emphasizes individual instruction.

The two most-often studied types of treatment are:

Academic or behavioural treatment

Typically, behavioral techniques are used to help the child respond and decrease symptoms. This might include positive reinforcement (food and rewards) to boost language and social skills. This training includes structured, skill-oriented instruction designed to boost social and language abilities. Training needs to begin as early as possible, since early intervention appears to influence brain development.

Most experts believe that modern treatment is most effective when carried out at home, although treatment may also take place in a psychiatric hospital, specialized school, or day care program.

Chemotherapy:

No single medicines or chemo has yet proved highly effective for the major features of autism. However, a variety of drugs can control self-injurious, aggressive, and other of the more difficult behaviors. Drugs also can control epilepsy, which afflicts up to 20% of people with autism.

Five types of drugs are sometimes prescribed to help the behavior problems of people with autism:

- stimulants, such as methylphenidate (Ritalin)
- antidepressants, such as fluroxamine (Luvox)
- opiate blockers, such as naltrexone (ReVia)
- antipsychotics
- tranquilizers

Today, most experts recommend a complex treatment regimen that begins early and continues through the teenage years. Behavioral therapies are used in conjunction with medications.

Many parents report success with megavitamin therapy. Some studies have shown that vitamin B_6 improves eye contact and speech and lessens tantrum behavior. Vitamin B_6 causes fewer side effects than other medications and is considered safe when used in appropriate doses. However, not many health practitioners advocate its use in the treatment of autism, citing that the studies showing its benefit were flawed.

DMG (dimethylglycine)

This compound, available in many health food stores, is legally classified as a food, not a vitamin or drug. Some researchers claim that it improves speech in children with autism. Those who respond to this treatment will usually do so within a week. Again, many doctors do not feel that the studies are adequate to promote this treatment.

Exercise/ Loco-motor activities:

One researcher in his study found that vigorous exercise (20 minutes or longer, three or four days a week) seems to decrease hyperactivity, aggression, self-injury and other autistic symptoms.

While there is no cure, with appropriate treatment the negative behaviors of autism may improve. Earlier generations placed autistic children in institutions; today, even severely disabled children can be helped in a less restrictive environment to develop to their highest potential. Many can eventually become more responsive to others as they learn to understand the world around them, and some can lead nearly normal lives.

People with autism have a normal life expectancy. Some people with autism can handle a job; they do best with structured jobs that involve a degree of repetition.

Mother- the most effective medicine for the autistic child:

Autism as we have seen, impacts communication, language and social skills. Some of the children in the sample had severely impaired verbal abilities. While they could utter a few words, these were usually heard when prompted, or sometimes used idiosyncratically and repetitively. Language as a tool for communicating needs and feelings was poorly developed. Parents and particularly mothers (who spent the greater part of the day with the child) thus saw themselves as the child's voice, the medium through which the child was rendered intelligible to the world and vice-versa. The child's personhood, his participation in social life were also constructed through talk. In the "mom sessions", mothers would delve into great detail on family activities, and the things their children were doing.

Vital and major needs of the Autistic Child:

There was near unanimity amongst the mothers interviewed that their responsibilities as mothers of autistic children outweighed the others as daughters, wives, daughters-inlaw, mothers of regularly developing children and professionals. This was a role in which they considered themselves irreplaceable. My own location as a widowed mother of an autistic child was invoked in this context, one mother said that my son was thriving despite his father's demise; she did not believe he would have done so well if I had died instead. The needs, routine an~ welfare of the autistic child often superseded those of other family members and the mother's own concerns, commitments and health. Mothers particularly felt they were doing an "injustice" to their regularly developing children, not paying enough attention to their husband's emotional and sexual needs and were unable and often unwilling to maintain social contacts with kin, friends and colleagues.

Mothers found scant time to devote to health, fitness, personal development, socializing with friends, leisure activities and sexuality, Their interactions with each other at the Special School were sometimes the only space where they could share their feelings and be understood. Talking with their own mothers or other relatives would often result in the reiteration of the 'tragedy'; they would often end up feeling worse than before.

Consistent Mothering :

Mothers confided that there were moments in which they felt so burdened by the demands of constant care that they felt like escaping or even committing suicide. Such feelings were particularly intense in the early years of the child's life when parents could not understand the reasons for the child's aberrant behaviour and because the shock of the diagnosis. Most of the mothers in the sample informed that they had now 'outgrown' these feelings of desperation and had become used to the child's condition.

➢ Attitudes towards Autistic Child:

Parents, Family & Society :-

In the recent past, placing a child in an institution left many families with feelings of guilt & inadequacy.

Whenever a child is born, the structure of the family changes. All families have to deal with that change, but the families of children with special needs face a special challenge. Some of their problems are unique, others differ only by degree. For instance the family of a child with special needs faces certain problems that families with healthy children do not face.

Family Needs & Feelings:-

At every stage of the child’s life, the families of those who have children with Special needs must deal with special problems. Parents of a young child with a disability need accurate information about their child’s condition. They have to decide what & how to tell relatives & friends about their child. They have to locate health & educational services. They worry about what others think about them & their child. They have to come to grips with their sadness, their guilt & their anxieties. Brothers and sisters have to deal with feelings of jealousy, the loss of their parents' energy and time, new responsibilities, & their fears. They also worry what their friends will think and say about their sibling with a disability.

Starting school is a change in routine. Most children find it difficult to adjust to that change, exceptional children & their families find it extremely difficult. Parents are expected to participate in the educational programme. They need to know about mainstreaming & the special class placement alternatives that can give them help at home. In addition they have to find after school care & determine the extent to which they want their child to participate in extracurricular activities. Brothers & sisters may be embarrassed, frustrated, disappointed & even angry when a sibling who is disabled is mainstreamed in their own school. Many siblings are expected to participate in special training programs & support groups that compete with other social & school activities. They also have to face the limitations that the disability may have on their siblings' future.

Impact of Autistic Child on the family:-

Each child is unique in this world so is each family, having its own strengths & weaknesses to face the challenges from time to time. Most of the parents and other family members naturally do start worrying about the future of the children with autism, feel sad or depressed at various stages of child's life, the social life of the family gets affected, they may like to keep themselves aloof from others and indulge less in recreational or leisure activities. Some families face rejection or neglect from the family members, friends or relatives & hence the interpersonal relationships gets strained leading to loss of support. Some generally, the mothers particularly gie up their jobs leading to greater financial strains, father may seek out jobs or transfers at places where services for such children are available .The effects however vary from family to family depending upon quality and quantity of emotional, financial & physical support available, degree of child's handicap & his age &whether the child has additional such as physical disability or behavior problems

Most consequential Impact on Mother:-

Most of the demands towards care of the children with special needs fall on mother. Some mothers are able to cop up better with the situation of having Autistic child than the others. However mothers are generally known to face maximum stress & pressures because of owning the major responsibilities of bringing up the child. Fathers generally do not make a bigger contribution than they would in ordinary families hence mother continue to struggle between meeting the household work and child's special needs if the mother happens to be a working lady she has to put up with much greater pressure. Stress is known to be higher in mother than in father of autistic children. Mothers are at a greater risk of developing stress related illness such as migraine, body aches & pains, hyper tension, anxiety & depression.

Impact on Father:-

Fathers generally take longer time to adjust the situation of having autistic child. It could be because they tend to spend less time with the child and also their contact with professionals may also be less, which gives them less chance to sort out their problems. At times having to put up with a male front up trying to solve all problems on ones own with less chance of sharing with others and hiding the true feelings about the handicapped child make it more difficult for them to adapt in a healthy way. Fathers too are known to suffer from depression though less than the mother and develop problems in marital relationship and personality difficulties. Their official work may get affected so also their relationship with employers or colleagues.

Impact on Brother and Sister:-

Sister or female siblings generally are known to get more affected as they are expected to share the burden of caring for the handicap brother or sister at the cost of their free time, recreational time, study time. In front of their friend they may feel embarrassed especially if their brother or sister behave in a socially unacceptable manner. Parents may put more pressure on normal sibling to over achieve in order to compensate the underachievement of the mentally retarded child. Parents may spend less time with the normal sibling making them fee neglected or jealous. They may miss out on sharing a relationship otherwise of having a normal sibling, worry about the future of their autistic sibling, worry about finding a spouse who would be accommodating and accept the autistic brother or sister and also fear themselves of producing a autistic child.

In this context, Rutter's (1987) concept of 'resilience' is useful. He defines resilience as 'the positive pole of individual differences in people's response to stress and adversity.' It is not conceived as the absence of pathology, but rather, the ability to cope with lives filled with difficulty. Resilience is fostered or enhanced by protective factors which help to ameliorate an individual's response to risk. In their insightful analysis of resilience amongst children of disabled parents, Booth and Booth (1998) analyse the .life-histories narrated by their respondents and attempt to identify the risk factors and protective factors that emerge from the narratives. They identify the following sets of protective factors:

1) **Personal protective factors:** This involves a sense of one's own worth as a person and the confidence that one can meet life's challenges. It involves the following abilities:

    - Sociability - a friendly and personable disposition, good communication skills, conventional looks and manner, good physical and mental health, socially acceptable behaviour;

    - Responsiveness to others - a capacity to maintain close and/or intimate relationships, expressions of love and feelings of responsibility for family members and protectiveness towards the disabled person;

    - Successful task accomplishment - including participation m voluntary activities, taking on responsibilities, having outside interests.

    The authors also include in their list individual factors like rebelliousness, ambitiousness, out-spokenness etc. which seemed to contribute to resilience in some cases.

2) **Protective mechanisms within the family:**

   - Warmth and mutuality - a feeling of being loved and valued, sharing family activities;
   - Stability- the lack of a separation, divorce illness or demise in the family:
   - Security - having a large supportive extended family, financial security, living in the same household as parents or other relatives.

3) **Protective social supports:** This is a key feature nurturing resilience. The authors identify two aspects of the wider social environment that act as buffers against stress:

   - Supportive relationships - school friends, friends in the neighborhood, helpful neighbors, good institutional supports from agencies like school, church, health center etc. and at least one supportive person outside the family.
   - Participation and involvement - living in a small, tightly knit community, visiting each others' houses, attending parties and celebrations, access to workplace opportunities, belonging to local clubs or associations.

Various Parenting Strategies for Autism

Autism is a complex developmental disability that is characterized by certain behaviors which typically begin to surface in the first three years of a child's life. Autism affects a child's ability to communicate and interact in social settings, and according to a 2009 study by the Centers for Disease Control, is occurring in one out of every 110 births. The stress of having to care for an autistic child can be very hard on families. An autistic child requires a lot of care and attention, but there are various parenting strategies to help families cope. It is important to remember, however, that each autistic child is different and therefore many strategies may need to be attempted or combined depending on what works best for your child.

Behavioral Therapy

If your child has been evaluated and is deemed to show behavioral signs that fall in the autistic spectrum, behavioral therapy has been shown to improve social and learning skills. The most effective therapy is known as applied behavioral analysis, or ABA therapy. Developed by Dr. O. Ivaar Lovaas, it is a highly structured early intervention program designed for children as young as two or three. ABA is lead by either a therapist or a parent and involves one-on-one instruction that rewards autistic children for developing good behaviors or reducing unwanted behaviors. ABA therapy can take place in the home and has been recognized to be effective in helping to develop language and cognitive skills, but criticized for being too rigid which slows social skill development. Another option is pivotal response therapy, or PRT, which is based on the ABA method but is more relaxed and child-centered. The therapy is guided by your child's interests in the hopes that positive pivotal behaviors will influence positive developmental growth.

Food Habits and Dietary Goals

There are some simple changes that can be made to your child's diet to help improve autistic symptoms. There are varying studies that cite a deficiency of certain vitamins or minerals in autistic children, but the most common vitamin supplement used is Vitamin B. Vitamin B is important for creating enzymes used by the brain, and many studies have shown that parents who introduce Vitamin B and magnesium supplements to their child's diet see great improvements. Decreased behavioral problems, better eye contact and improved learning and attention span are some of the changes parents see. Cod liver oil supplements and Vitamin C also have shown positive results. Removing certain foods or chemicals from your child's diet can be helpful, as well. Many autistic children have trouble digesting proteins such as gluten and casein, which if not properly digested and broken down, can affect brain functions. It is important, however, to consult a nutritionist or specialist before completely removing gluten or casein from a child's diet, as this can lead to withdrawal symptoms.

Complementary Options

In addition to behavioral therapy and dietary changes, there are other treatment options that can be used to help with your child's communication skills and ability to interact socially. Referred to as complementary approaches, the use of music, art or animals in therapy has been shown to improve social skills. Music and art therapies allow autistic children to express themselves and music especially has been shown to help with language comprehension.

10 Tips for Parents of Autistic Children

Parents of autistic children have different difficulties from other parents. They have different issues that they could handle it with different tips. And, you can find those tips in this article.

1-) Understand Child and His/ Her Behaviors

These children are not bad and they don’t have bad intentions. They just act differently. According to the some researches, autistic children more able to get and perceive eye contact. You need to understand your child and his feeling. What makes him uncomfortable? If you understand what effects your child mostly, you can get closer to the solution.

2-) Try to develop Positive Reactions

Your child might have unusual behaviors. It would be considered weird by other people. The most important one is you. You have to control your reactions and show positive behaviors to your child.

3-) Provide immense Care

Because, that is what they need. You can even do that with a lovely hug. Show him that you love and care about him.

4-) Avoid Overmuch

If your children overreacts for some situations like parks or carnival, try to keep him away from these situations if it is possible. If you can't avoid, try to distract him by a toy a play.

5-) Ignore the Traditions and Orthodox beliefs

As we said before, they need special care and treatment. So, you need to be open new parenting methods.

6-) Proud of Him /Her

Maybe, he cannot be star in his environment. But, whatever he does, show him you are proud of him. Always encourage him. He needs your support.

7-) Never ever get annoyed

Don't forget that he does not in purpose what ever he does. As we said, autistic children don't have bad intentions. He could show different reactions and he could act differently. Even he does something bad, it is not his intention.

8-) Arrange a Safe and healthy Environment

Make sure that the environment is safe enough for your child. Lock the door, remove the corners and get some fences.

9) Spare your time for fun

It could be stressful for parents but, you can also have fun with your child. Take him out, run and scream with him. When he smiles, you smile.

10)Avoid aggressiveness

He would make some mistakes that could make you angry. Don't show him your anger. Don't let him see. Control yourself. Whenever your child makes mistake, try to explain the right instead of shouting, give instructions smoothly and always be polite for his/ her mistake.

He is your child, he is a gift which is sent by god. Always remember this fact and try to do your best parenting. Parents can start learning the advices and tips for parents of autistic children. They could help the parents having child with autism.

Following are the several disabilities and problems can be seen among autistic children one study also found the result and the key areas for the disabilities among the autistic children.

- **Co-morbidities with Autistic Spectrum Disorders**

  - ***Psychiatric Disorders:*** The co-morbid psychiatric disorders include Attention Deficit Hyperactivity Disorder, anxiety disorders, disruptive behavior disorders, mood disorders, Tics, Tourette Disorder and depression.

  - ***Intellectual Disabilities (previously referred to as Mental Retardation)****:* About 41% children with ASD have intellectual disabilities (i.e. IQ < 70)†

  - ***Epilepsy / Seizures****:* The overall prevalence of epilepsy in children with ASD is 25-30%.

The presentation is bimodal, with onset most likely to occur in infancy, with a second peak in early adolescence. All types of seizures may occur. Children with Tuberous clerosis are more likely to have epilepsy and autistic disorder.

  - ***Feeding Disturbances and Gastrointestinal Problems:*** Feeding habits and food preferences have been commonly associated in children with ASD. The frequently reported food disturbances are low levels of food acceptance, food selectivity by type and food selectivity by texture. Gastrointestinal problems are frequently reported (30%) and can be severe in nature.

  - ***Sleep Disturbances:*** Sleep problems have been reported in 44–83 percent of children (aged 3–15 years) with autism. Parasomnias (behaviors like breath cessations and bruxism) have also been reported.

  - ***Hearing Impairment:*** The vast majority of children have normal hearing function.

Nevertheless studies have reported profound bilateral hearing loss in 3.5% of cases of autistic children, prevalence greater than that seen in the general population.

❖ Natural History / Course of Autism Spectrum Disorder

- It is very important to remember that the clinical spectrum changes with age and level of developmental maturity.
- The specific characteristics change as the child grows older, but the deficits continue into and through adult life with broadly similar patterns.
- During infancy, most children with ASD have a history of delayed language development. Some children (25-30%)‡ begin to say few words and then stop speaking often between 15 to24 months of age. Often delays and deviations in language become apparent during the 2nd or 3rd year of age and are a common cause of seeking professional help.
- As the child develops, the child may become more willing to be passively engaged in social interaction, but their behavior is still deviant with lack of awareness of other people's boundaries and/or inappropriate intrusiveness.
- Hyperactivity improves and ritualistic behaviors start decreasing during adolescence.

Depression may develop in some high functioning autistic individuals who have limited social and language skills when they struggle with the normal desire to be a part of a group.

❖ VARIANCE TOWARDS DIAGNOSES

- Acquired epileptic aphasia (Landau-Kleffner syndrome) - History of epileptic seizures (first manifestation in up to 60% patients), clinical course, EEG.
- Stereotypic Movement Disorder
- Severe or profound Intellectual disabilities
- Undiagnosed hearing impairment

❖ DIAGNOSIS

➢ Diagnostic Criteria

- **Consensus Clinical Criteria (CCC)– ASD** is defined as group of developmental disorders characterized by qualitative impairment in reciprocal social interactions along with qualitative impairment in communication and / or restrictive, repetitive and stereotyped pattern of behavior, interests and activities.

The criteria for diagnosis is based on best currently available evidence and / or consensus among national and international experts, using minimal investigations to serve the needs of resource constrained settings.

- **Instructions for Evaluation**

1. In evaluating a child, clinicians rely on questionnaires and direct observation (both structured and unstructured settings) to arrive at a diagnosis
2. In the current program, DSM-IV TR criteria are used for the diagnosis of autistic spectrum disorders
3. For the ease of application, a part of DSM-IV TR criteria have been converted into a questionnaire. This consists of questions to elicit responses in three relevant categories:
    a. Qualitative impairment in social interaction,
    b. Communication, and
    c. Restrictive, repetitive and stereotyped pattern of behavior, interests and activities

Treatment for Children With Autism

Child development experts agree that a child with autism should receive treatment as soon after diagnosis as possible. There is no cure for autism, but early intervention using skills-training and behavior modification techniques can yield good results. This type of educational and behavioral treatment tackles autism symptoms -- impaired social interaction, communication problems, and repetitive behaviors -- and can boost an autistic child's chances of being able to go to school and participate in normal activities.

Other treatment options for children with autism include:

Medication. Doctors sometimes prescribe it for children with autism if they have other symptoms, including depression, anxiety, seizures, or hyperactivity.

Alternative therapies. This might include vitamin treatments, changes in diet, and a procedure called "chelation" that attempts to remove heavy metals from the blood. Although many parents insist these types of treatment work, researchers have not scientifically proven them effective for children with autism, either for symptoms or long-term outcomes.

How one can assist the parent having an autistic child:

Those Parents have a child with autism, it is important to get support. The day-to-day care of children with autism can be stressful. Making sure the child gets the help he or she needs can also pose a challenge, depending on whether quality support services are available in parent’s area. At the same time, parents are likely to have ongoing worries about the child's prognosis and long-term well being. For all these reasons, the need to take care of parents by themselves, as well as their child. Make an effort to reach out and find the support which the parent need from family, relatives, and other surroundings.

- **Aware and Educate the best parenthood.** Try your best that the parent can learn all about caring and upbringing of children with autism. Read about children with autism in other sections of this Web site. Consult governmental and nonprofit organizations for more information on children with autism. Stay up to date on current research findings.

- **Follow referrals and Build a strong support system.** Seek out local groups and parent network organizations for families of children with autism. Ask your physician or child developmental specialist for referrals. Join online chat groups for parents of children with autism.

- **Make time for own and the relationships.** Try to schedule regular dates with your partner and outings with friends. Keep up with the activities in which parents can get rid off from stress and anxiety.

- **Get help.** Seek help of the spouse who is feeling persistently overwhelmed or depressed, or the stress of caring for a disabled child is affecting your relationship. Your physician can help you find a qualified individual, couples, or family therapist.

What should be the attitude of the parents towards their challenged child?

1. MAKE YOUR ENDEAVOURS TO PUT EMOTIONAL HEALTH:

If parents do not tend to their own emotional needs fist it could interfere in their ability to facilitate positive development in their child. A major issue for parents in giving up the dream of a perfect child. In addition, they must knock out of any expectations they had for their child - including college, marriage, and procreation – they are no longer “givens.” Suddenly parents must face the facts, that their child will depend on them for most if not all his/her entire life. What happens when parents are no longer able to care for the child? In a heartbeats time, parents are flooded with having to learn about a disability they had never or only vaguely heard of. Parents encounter professionals, teachers, doctors, and other individuals to give advise and teachings but they would rather not have to deal with these professionals in the first place! All these professionals are like knives digging into the parents back while they are still in the grieving stage. It is sometimes very tempting to launch into a knowledge acquisition phase and ignore their most important feelings—the loss of the typically developing child they once dreamed about. If the parents of autistic child take care of your own emotional well-being first, you’ll have lots more energy to move into the next stages. It is very important for parents to work through their own emotional reactions. Both parents as individuals, and the marriage, will surely be affected by the child’s developmental challenges. Also be prepare to get professional help as soon as the parent can, to ensure that they can give their best to their child. The parents may not want to listen but with open ears child voice will be heard to them.

2. OBSERVE THE REACTIONS AND RESPONSE OF YOUR CHILD

The next common challenge that faces most parents of children with autism involves the child’s emotional reaction to the parent. Parents by nature are programmed to respond to vulnerable creatures and thus in turn eliciting a response in us. Developmentally challenged infants and toddlers do not necessarily provide us with the responses that trigger our innate impulses to care for them. Some children initially don’t respond much at all, others have responses that we don’t understand, and many respond in a different way every time the parent approaches. These unexpected and confusing response styles leave parents with a sense of inadequacy.

All parents instinctually, spend time observing their child. But, as parents of a child with autism, it is important to remind themselves on a regular basis that, although their child is not responding in the way the parent thought he/she would, they still are responding. The parent shall need to obtain the role of detective, discovering clues and solutions to optimize responses from their child.

Try to find out what pleasurable and fun thing that they can give to their child . Even a non-response is a response. It usually means that the baby/child is some what uncomfortable with the approach or with the stimuli, and instinctually pulls away for protection. Monitor how he reacts to various people, places and things. Keep a diary or a record and parents shall start to discover patterns of behavior. These records will help the parents to learn and to adapt themselves to their child’s changing moods. Keep in mind that their everyday child’s emotional responses may be what the parents want or anticipate but they do not mean that they are a failure.

3.JUST TRY TO MAKE YOUR CHILD HAPPY ACCORDING TO HIS/HER OWN LIKINGS:

Joining your child in their world requires an essential parenting skill—imitate and follow. Don’t make demands, don’t ask him/her to perform (i.e., “What color is this?” or “What does a cow say?”), and don’t direct the play. This will not be an easy task though it might sound simple. As parents we all want to feel proud of what our children know and do. We get great satisfaction in asking them to show off, especially in front of others so they can see what great parents we are. However, most children don’t like to be drilled (nor do adults, for that matter), and when too much of this occurs, the child with autism may simply withdraw, or do the opposite, have a tantrum. If parents are able to enjoy what comes from your child he/she will in turn enjoy the world they live in more. Granted, as parents we will always be tickled by our child's responses to our approaches and or questions, but expecting too much of this will backfire on you. Instead, join in, try to do comprehensive conversation between the parents and children . Finally, don't be afraid to add to the play with own creations in the hope that the child will someday become interested in them, too. If the child has limited awareness of others, parent can gently create situations in the playing process to get child to notice to parents.

Most children with autism develop special interests. Parents are often encouraged by professionals to distract the child from their particular special interest. However, sometimes making use of that special interest is a great way to achieve long periods of engagement with your child. There is a fine line between discouraging a child's special interest and passing along the message that what interests him/her in turn interests to them. Encouraging and motivating the child's interest can lead to emotional engagement and provide the child with the sense of being valued.

4. PUT WORDS TO YOUR CHILD'S FEELINGS.

In each cases always appreciate the child, and label the child's feelings. Children who are able to identify their internal experiences have a better sense of who they are. Many children with special needs have a difficult time identifying abstract concepts, and feelings are abstract. Therefore, as a young child learning about the world and about himself, one important area of learning has to do with emotions. If the parents limit their child they will most likely exhibit anger (i.e., throwing things, tantrumming, etc.). As a parent they should encouraged to label their child's emotion—"You're so mad when mommy says you have to stop playing." You may, of course, need to make other interventions, but don't forget to label that feeling—even for young infants!

5. ADMIRE AND MOTIVATE YOUR CHILD'S BEHAVIOR

As a parent , they are always to do critics and scold if child gets mistakes in any task, especially when we are overwhelmed and faced with difficult behaviors. However, we must remember the basic behavioral principles: whatever behavior the parents pay attention to - and attention can be either positive or negative - will increase. Therefore, if the parents are criticizing and not praising, the behavior they criticize will increase. However, if the parents add praise to the positive, parents will get more of it. Parents need to put themselves on a diet. No, not a weight loss diet but a behavioral diet—challenge themselves to praise their child every 2-3 minutes. Think of praising the infant or child as providing him/her with a "gleaming" mirror of himself/herself in the glow in their eyes when they look at him/her, in the gentleness of their voice when they talk to him/her, or in the soothing sense of their touch. Let the child know that they are wonderful and special in their own way and worthwhile at least 100 times each day!

Precautions and Steps for the Improvement in Child with Autism

Autism Home Program for Parents

Autism home program for parents can be a valuable resource for families. Autism home programs can teach parents how to develop effective autism home treatment plans. The programs also help families with newly diagnosed children learn more about autism. Learn about autism home programs and how they benefit children with autism.

About Autism Home Programs for Parents

An autism home program for parents refers to an autism treatment program designed to be organized by parents in the family residence. A number of home programs follow a certain type of treatment protocol, such as applied behavior analysis, to address various autism symptoms and characteristics of autism. Families can also choose to build home programs that include a combination of different types of therapies if it works better for the person with autism.

Parents can also choose to create a complete home-based autism treatment program for their children or a program that complements autism therapy outside of the home. Autism home programs can work for home schooled children as well as children who attend school. In fact, a home program can help many children who attend school develop stronger communication and social skills to help them succeed at school. Parents interested in autism home treatment can choose to enroll in a full-service autism program, which renders all necessary program steps and instructions, or design their own program by hiring individual therapists and teachers. Many parents do a combination of these options.

Following are the best Examples for Autism Home Program

There are many options for autism home programs at various locations. One of the leading full-service home programs is the Son-Rise Program.

The Son-Rise Program

The Autism Treatment Center of America offers the *Son-Rise Program*, an autism program developed by Barry Neil Kaufman and his wife, Samahria Lyte Kaufman, based upon the successful treatment plan that helped their autistic son, Raun. According to the Son-Rise website, Raun no longer exhibits any symptoms of autism.

The Son-Rise treatment model emphasizes positive reinforcement, one-to-one teaching and interactive play strategies for parents to learn how to help their autistic children improve language, communication and social skills. Son-Rise views autism as a neurological condition and not a behavioral problem. For example, the program teaches that parents should respect a child's stimming and repetitive behavior, and join the child in the behavior because it encourages trust, social interaction and communication. The Son-Rise program can work well combined with other types of therapies, especially sensory integration therapy, biomedical intervention, gluten-free casein-free diets, dietary goals and auditory integration therapy. It also works well for home-schooled children as well as children who attend school. In fact, Son-Rise can help a child prepare to enter a mainstream school.

To learn the Son-Rise program, parent must attend at least one instructional course at the Autism Treatment Center in Sheffield, Massachusetts. Parents can choose between the Son-Rise Program Start Up, a five-day instructional course to learn program basics, or the Son-Rise Sequence, a package that includes a program foundation class and two additional advanced training courses. Additional training courses as well as instructional books, CDs and DVDs are also available.

After completing the program, Son-Rise provides support services through phone consultations, video consultations and at-home visits from local Son-Rise certified teachers.

Other Autism Home Programs

Parents can design an effective autism home program based upon the following types of treatment methods:

- **Relationship Development Intervention (RDI):** Dr. Steven Gutstein developed RDI, a parent-child centered program that focuses on improving social interaction and emotional responses. Parents and an RDI consultant work with the child in one-to-one activities and gradually work toward expanding the child's social interaction opportunities. The RDI program works on helping a child understand nonverbal signs, appropriate social behavior and greater awareness of the emotions of others.

- **Applied Behavioral Analysis (ABA):** ABA is a one-to-one treatment plan that focuses on rewarding good behavior and neglecting bad behavior, in order to encourage appropriate responses. Parents and children work with an ABA therapist who uses positive reinforcement of good behavior, repetition and structured teaching improve announcement, social interaction and language skills.

- **Floor time:** The floor time treatment method involves child-led interaction to teach through play. The child-led interaction builds trust and encourages social interaction and communication. Over time, the parent can expand the child's social interaction and selection of activities at the child's pace.

- **Wraparound:** Wraparound is a program that provides services at home, school and community environments according to the child's specific needs. A therapist works one-to-one with the child using approaches like separate trial, applied behavioral analysis and Floor time many parents combine one or more autism treatments in their home programs.

Benefits of Autism Home Programs

Autism home programs allow parents to have full control over every aspect of their child's treatment. Many parents prefer home programs because they can work closely with their child and tailor treatments to the child's specific needs. The one-to-one activities of a home program help foster a close relationship between parents and autistic children. In addition, the fact that the home is also a classroom helps maintain the flow of learning for the child.

Tips for Parenting a Child with Autism

The shock of finding out your child has autism is life-changing for most parents. But new findings show parents can fare well emotionally and still have a strong bond with their child.

Studies into the coping skills of mothers of children with autism confirm that moms are more likely to report "poor or fair" emotional and mental health than other moms, but they are also more likely to show remarkable strengths.

Autism Spectrum Disorders

The forms of autism are thought to overlap considerably. But the fact that there is wide variation in symptoms among children with autism led to the concept of autism spectrum disorder.

Autism seems to be on the rise, and autism spectrum disorders affect between two and six children out of every 1,000 in the U.S. It's unclear, though, whether the growing incidence of autism represents a real increase or just improved detection.

Early diagnosis of an autism spectrum disorder is important. That's because detection leads to treatment, and with early treatment, a child with autism can gain improved language and social skills.

These findings, published in the journal *Pediatrics*, come from a nationally representative survey of almost 62,000 mothers of school-aged children, including 364 mothers of children with autism. Researchers concluded that moms of children with autism were just as likely as other moms to report having a close relationship with their child and five times as likely to do so as mothers of children who had other developmental problems (not including autism).

Autism and other pervasive developmental disorders (or PDD) typically begin before age 3. They are a complex group of developmental disabilities marked by great difficulty in social interaction and communication. Difficulties on the spectrum range from mild to severe.

If parents have a child with autism, they know how this developmental disorder can unsettle every part of the life and the relationships, physical, mental and emotional health, and career ambitions. But there is always positivism. Consider the following strategies as parents tackle the special challenges and receive the unique joys of parenting a child with autism.

1 DEVELOP HABIT OF BEING LEARNING ABOUT AUTISM:

No one can't "catch" autism. It is either have it or don't. And today, about one in 91 children has been diagnosed with autism or an autism spectrum disorder (also called ASD), which encompasses several related disorders, such as Asperger's syndrome. They are all complex developmental disabilities that affect the development of a child's social skills, communication skills, and behavior.

Autism is usually detected during a child's influential years, so experts know that early diagnosis, intermediation, and treatment are the keys to helping young children with autism develop to their full potential. The primary and prominent goal of autism treatment is to improve the overall ability and to overcome potentiality of the child to function.

Because autism symptoms and behaviors often change over time, treatment strategies are tailored to the child's needs and available family resources. In general, however, children with autism respond best to highly structured and specialized treatment. A program that addresses helping parents and improving communication, social, behavioral, adaptive, and learning aspects of a child's life will be most successful.

Consult to doctor about the best autism treatments and goals for educational services, so the parents and the child can take advantage of all available resources.

Refer the relevant literature on autism so the parents can understand the symptoms and behaviors and the differences in medications or alternative therapies. Communicate with other professionals and parents and learn from those who've crossed this bridge before you as they share insights into common autism concerns. In addition, become very familiar with public policies and public services, resources available for them so parents can be child's advocate in gaining the best education and care possible. Make sure, for example, that plans (504 or IEP) are in place for child to receive therapies at school.

2. KEEP YOURSELF SOCIALLY ENGAGED ALWAYS

Parenting a child with any chronic illness is emotional; it affects every part of their being. But the day-to-day care of children with autism is especially stressful because of the lack of essential social interaction and communication between the child and adult. Making sure your child gets the help he needs can also pose a challenge, depending on whether quality support services are available in your area. At the same time, you are likely to have ongoing worries about your child's prognosis and long-term well-being. For all these reasons, parents need to find strong social support for themselves , as well as for their child.

Gathering your support network involves knowing ahead of time whom you can call for different types of support, even for emergencies, including:

- **Emotional:** A close friend or family member who is a confidant and whom you trust with your most personal feelings and concerns
- **Social:** A friend or colleague you enjoy being with and who helps you survive disappointments and shares your victories
- **Informational:** Your child's doctor, teachers, therapists, or other caregivers you can ask for advice on major decisions regarding his or her treatment
- **Practical:** A neighbor or close friend who will help you out in a pinch.

In addition to these different types of support, you can seek out local groups and parent network organizations for families of children with autism. Consult to doctor or child developmental specialist for referrals. Join online chat groups for parents of children with autism.

The more you know about autism and the stronger your support network, the more empowered you will be to live confidently, knowing that your child can get the help he or she deserves.

3.MAKE AWARE THE FAMILY WITH REGARAD TO AUTISM

Many moms of kids with autism talk about feeling isolated. Once a child is diagnosed, they often find that family members stop asking about the child or the child is left out of birthday parties or other family gatherings.

Sometimes spouses and other children admit to feeling stressed, lonely, even angry, as all attention is focused on the child with autism. While these feelings are natural, you can help your family members cope by educating them about autism and the child's specific needs.

Training family members about autism and how to effectively manage the symptoms has been shown to reduce family stress and improve the functioning of the child with autism. Some families will need more outside assistance than others, depending on their internal functioning, established support systems, and financial situation.

In addition, plan outings with other families who have a child with autism. There are many families who share your concerns and daily challenges. Talking openly with these families can give you new insight and better ways of coping. Local and national groups can help connect families and provide much-needed sources of information. Most health professionals can recommend some of these organizations.

4. PERUSE THE RECOMMENDATIONS FOR ITS TREATMENT:

Child development experts agree that a child with autism should receive treatment as soon after diagnosis as possible. There is no cure for autism, but early intervention using skills training and behavior modification techniques can yield good results. This type of educational and behavioral treatment tackles autism symptoms -- impaired social interaction, communication problems, and repetitive behaviors -- and can boost an autistic child's chances of being able to go to school and participate in normal activities.

The American Academy of Pediatrics (AAP) recommends the following strategies for helping a child with autism improve overall function and reach his or her potential:

- **Behavioral training and management.** Behavioral training and management uses positive reinforcement, self-help, and social skills training to improve behavior and communication. Many types of treatments have been developed, including Applied Behavioral Analysis (ABA), Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), and sensory integration.

- **Specialized therapies.** Specialized therapies include speech, occupational, and physical therapy. These therapies are important components of managing autism and should all be included in various aspects of the child's treatment program.

Speech therapy can help a child with autism improve language and social skills to communicate more effectively. Occupational and physical therapy can help improve any deficiencies in coordination and motor skills. Occupational therapy may also help a child with autism to learn to process information from the senses (sight, sound, hearing, touch, and smell) in more manageable ways.

Remember, when considering any type of treatment for your child, it is important to know the source of information and to ensure that studies are scientifically sound. Accounts of individual success are not sufficient evidence to support using a treatment. Look for large, controlled studies to validate claims.

5. FOCUS MAJORLY ON BEHAVIOURAL TRAINING

Behavioral training teaches people of all ages with autism how to communicate appropriately. This type of training can reduce behavior problems and improve adaptation skills.

Both behavioral training and behavioral management use positive reinforcement to improve behavior. These therapies also use social skills training to improve communication. The specific program should be chosen according to the child's needs. As an example, a high-functioning child with autism may be enrolled in mainstream classrooms and child care facilities. The behaviors of other normally developing children can provide examples for the child with autism to follow. However, other children with autism are overly stimulated in a regular classroom and work best in smaller, highly structured environments.

Consistent use of these behavioral interventions produces the best results for the child with autism. The child's functional abilities, behavior, and daily environment should be thoroughly assessed before behavioral training and management begins. Parents, other family members, teachers, and caregivers of the autistic child should all be trained in these techniques.

6. MEDICATE THE CHILD AS PER HIS/HER REQUIREMENTS

While there is no medication for autism, there are drugs for specific symptoms that kids with autism might display. As an example, the FDA approved Risperdal in 2006 for the treatment of irritability in children and teens with autism. Short attention spans can sometimes be improved with stimulant drugs that are used to treat ADD or ADHD.

Drugs have a limited role in improving symptoms of autism. However, some may help prevent self-injury and other behaviors that are causing difficulty. Medicines may also take a child with autism to a functional level at which they can benefit from other treatments.

The American Academy of Pediatrics suggests targeting the main problem behaviors when considering medicines. Medicines that are sometimes used to treat behaviors related to autism include selective serotonin reuptake inhibitors (antidepressants) and antipsychotic medicines.

Selective serotonin reuptake inhibitors (SSRIs) include Celexa, Prozac, and Zoloft, for example. The high rate of effectiveness for depression, anxiety, and obsessive, stereotypical behaviors has made these medicines a popular choice for managing autism. They may also improve general behavior, language, learning, and socialization. In addition, although SSRIs have side effects such as weight gain or loss, insomnia or drowsiness, and increased agitation, they tend to be less serious than those of antipsychotic medicines.

Antipsychotic medicines, such as Haldol, Risperdal, Zyprexa, and thioridazine work by changing the effects of brain chemicals. They may help decrease problem behaviors that can occur with autism. A well-designed study found that Risperdal was effective for the treatment of tantrums, aggression, and self-harming behavior in children with autism.

However, these medicines can have side effects, including sleepiness, tremors, and weight gain. Their use is usually considered only after behavior management has failed to address the problem behaviors.

7. DIET – THE MOST IMPORTANT ONE SHOULD LEARN MORE TO THE EXTENT POSSIBLE

Diet changes are based on the idea that food allergies cause symptoms of autism, and an insufficiency of a specific vitamin or mineral may cause some autistic symptoms. If you decide to try a special diet for a given period of time, be sure you talk to your pediatrician and a registered dietitian. The child's nutritional status must be assessed and carefully measured.

One diet that some parents have found helpful is a gluten-free, casein-free (GFCF) diet. Gluten is a casein-like substance found in wheat, oats, rye, and barley. Casein is the principal protein in dairy products such as milk.

The theory of the GFCF diet is that in autistic children these proteins result in an overproduction of opiates in the brain, contributing to social awkwardness and thwarting brain maturation. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is extremely difficult.

Parents of a child with autism who also has food allergies or intolerance may be more likely to attempt the restrictive GFCF diet. However, food sensitivities are not proven to be more common in children with autism than in normally developing children. Still, some parents claim benefit from restrictive diets.

One supplement some parents feel is helpful for a child with autism is vitamin B-6, which is taken with a magnesium supplement. The results of research studies are mixed on vitamin B-6 and magnesium supplementation. While some children respond positively, others respond negatively or not at all.

8. BE CAUTIOUS WITH THE THERAPIES WHICH ARE NOT PROVED:

The safety and effectiveness of some therapies used to treat autism are not known. Many unproven treatments circulate through web sites, word of mouth, or the media. Most have not been subjected to thorough, sound research and are considered nonstandard and controversial. Even if someone else has found tremendous success with an "unproven" therapy, it's important to be cautious about a treatment for autism if:

- The autism treatment is based upon oversimplified scientific theories.
- It benefits more than one condition.
- It provides dramatic and "miraculous" results.
- The only available evidence is based upon a few stories (anecdotal evidence), not scientific research.
- Specific treatment goals or target behaviors are not identified.
- Controlled, scientific research is said not to be needed because there are no risks or side effects.

Examples of nonstandard, unproven therapies for autism that are receiving attention include:

- **Immune globulin therapy.** An intravenous (IV) injection of immune globulin is based on the assumption that autism is caused by an autoimmune abnormality.
- **Secreting.** This treatment uses an IV injection of secreting (a hormone that stimulates the pancreas and liver) to manage autistic behavior. Anecdotal reports have shown improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. Several clinical trials conducted in the last

few years have found no significant improvements in symptoms between children with autism who received secreting and those who received a placebo.

- **Creation therapy.** Mercury exposure as a cause of autism is the basis for this therapy, which uses medications to help the body eliminate the toxins. Children with autism often have a craving for nonfood items or unusual diets that may result in mercury exposure; therefore, mercury exposure may be more of an effect of autism than a cause.
- **Auditory integration training (AIT).** Based upon a theory that autism is caused by hearing problems that result in distorted sounds or oversensitivity to noises, this treatment delivers music through special devices.
- **Facilitated communication.** This method uses a keyboard to assist communication. It has not been found to be helpful and in some cases has been harmful.

9. TAKE BREAKES TIMELY AND ACCORDINGLY AS PER REQUIREMENT:

Many parents of children with autism feel exhausted, overwhelmed, and sometimes defeated. They talk about difficulties in their marriage and other relationships. While there is no quick fix for resolving detrimental emotions, you can take measures to protect yourself so your child's condition does not get in the way of your physical or emotional health.

Review your calendar weekly. In the midst of the many appointments your child might have with speech or occupational therapists or other health care professionals write in "appointments" for yourself and your relationships. Schedule regular dates with your partner, other children in the family, and close friends.

Exercise regularly. Keep up with the physical activities you enjoy. Eat a balanced diet and stay at a normal weight. Staying fit and healthy is essential to your physical and emotional wellness -- and to caring for a child with special needs.

Seek help if you or your partner is feeling persistently overwhelmed or depressed, or the stress of caring for child with autism is affecting your family relationship. Watch for signs of anger, resentment, or opposition from other children in the family. Your doctor can help you find a qualified individual, couples, or family therapist to help Parents figure out the best ways to cope.

In addition, plan time for a break away from a child with autism. Trained personnel can help relieve Parents from these duties as needed. These breaks can help families communicate in a less stressful context and allow parents to focus on their relationships with their other children. Having regular breaks may also help a family continue to care for a child with autism at home, rather than becoming so exhausted that they resort to institutional care. Government programs exist to help families who cannot afford this occasional care.

Moms of kids with autism talk about having very close relationships with their children, as they organize the child's therapy, hire specialists, purchase supplies, and act as their child's advocate to receive the best treatment. The biggest payoff comes from a unique bond Parents can have with Parents are child and the joy Parents receive in every developmental accomplishment.

There's no doubt that raising a child with autism is the ultimate parenting challenge. But with the necessary support and ongoing training, Parents and Parents are family can learn how to cope and work as a team.

HOW ONE CAN HELP OUT THE CHILDREN WITH AUTISM?

The best ever strategies and Parenting Tips are described herewith:

There are many things parents can do to help children with autism overcome their challenges. But it's also important to make sure Parents get the support Parents need. When Parents are looking after a child with autism, taking care of Parents themselves is not an act of selfishness–it's a necessity. Being emotionally strong allows Parents to be the best parent Parents can be to Parents are child in need. These parenting tips can help by making life with an autistic child easier.

A parent’s guide to autism treatment and support

If Parents have recently learned that Parents are child has or might have an autism spectrum disorder, Parents are probably wondering and worrying about what comes next. No parent is ever prepared to hear that a child is anything other than happy and healthy, and a diagnosis of autism can be particularly frightening. Parents may be unsure about how to best help Parents are child or confused by conflicting treatment advice. Or Parents may have been told that autism is an incurable, lifelong condition, leaving Parents concerned that nothing Parents do will make a difference.

While it is true that autism is not something a person simply "grows out of," there are many treatments that can help children learn new skills and overcome a wide variety of developmental challenges. From free government services to in-home behavioral therapy and school-based programs, assistance is available to meet Parents are child's special needs. With the right treatment plan, and a lot of love and support, Parents are child can learn, grow, and thrive.

Don’t wait for a diagnosis

As the parent of a child with autism or related developmental delays, the best thing Parents can do is to start treatment right away. **Seek hel**p as soon as Parents suspect something’s wrong. Don't wait to see if Parents are child will catch up later or outgrow the problem. Don't even wait for an official diagnosis. The earlier children with autism spectrum disorders get help, the greater their chance of treatment success. Early intervention is the most effective way to speed up Parents child's development and reduce the symptoms of autism.

Here are the tips for parents with autistic child:

- **Learn about autism.** The more Parents know about autism spectrum disorders, the better equipped Parents will be to make informed decisions for the child. Educate Parents about the treatment options, ask questions, and participate in all treatment decisions.

- **Become an expert on Parents’ child.** Figure out what triggers Parents kid’s “bad” or disruptive behaviors and what elicits a positive response. What does Parents autistic child find stressful? Calming? Uncomfortable? Enjoyable? If Parents understand what affects Parents child, Parents will be better at troubleshooting problems and preventing situations that cause difficulties.

- **Accept child in all sense** Rather than focusing on how autistic child is different from other children and what he or she is "missing," practice acceptance. Enjoy Parents kid's special quirks, celebrate small successes, and stop comparing Parents child to others. Feeling unconditionally loved and accepted will help Parents child more than anything else.

- **Never give up.** It's impossible to predict the course of an autism spectrum disorder. Don't jump to conclusions about what life is going to be like for Parents child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.

Helping children with autism tip 1: Provide structure and safety

Learning all Parents can about autism and getting involved in treatment will go a long way toward helping the child. Additionally, the following tips will make daily home life easier for both Parents and their autistic child:

- **Be consistent.** Children with autism have a hard time adapting what they've learned in one setting (such as the therapist's office or school) to others, including the home. For example, Parents and child may use sign language at school to communicate, but never think to do so at home. Creating consistency in Parents are child's environment is the best way to reinforce learning. Find out what Parents are child's therapists are doing and continue their techniques at home. Explore the possibility of having therapy take place in more than one place in order to encourage Parents are child to transfer what he or she has learned from one environment to another. It's also important to be consistent in the way Parents interact with Parents child and deal with challenging behaviors.

- **Be punctual with to a schedule .** Children with autism tend to do best when they have a highly-structured schedule or routine. Again, this goes back to the consistency they both need and crave. Set up a schedule for Parents' child, with regular times for meals, therapy, school, and bedtime. Try to keep disruptions to this routine to a minimum. If there is an unavoidable schedule change, prepare Parents' child for it in advance.

- **Appreciate good behavior..** Positive reinforcement can go a long way with children with autism, so make an effort to “catch them doing something good.” Praise them when they act appropriately or learn a new skill, being very specific about what behavior they’re being praised for. Also look for other ways to reward them for good behavior, such as giving them a sticker or letting them play with a favorite toy.

- **Establish safe and homely environment:** Carve out a private space in home where the child can relax, feel secure, and be safe. This will involve organizing and setting boundaries in ways the child can understand. Visual cues can be helpful (colored tape marking areas that are off limits, labeling items in the house with pictures). Parents may also need to safety proof the house, particularly if the child is prone to tantrums or other self-injurious behaviors.

Helping children with autism tip 2: Find nonverbal ways to connect

Connecting with a child with autism can be challenging, but Parents don’t need to talk in order to communicate and bond. Parents communicate by the way Parents look at the child, the way Parents touch him or her, and by the tone of parent’s voice and your body language. The child is also communicating with Parents, even if he or she never speaks. Parents just need to learn the language.

- **Look for nonverbal cues.** If Parents are observant and aware, Parents can learn to pick up on the nonverbal cues that children with autism use to communicate. Pay attention to the kinds of sounds they make, their facial expressions, and the gestures they use when they’re tired, hungry, or want something.

- **Figure out the need behind the tantrum**. It’s only natural to feel upset when Parents are misunderstood or ignored, and it’s no different for children with autism. When children with autism act out, it’s often because Parents are not picking up on their nonverbal cues. Throwing a tantrum is their way communicating their frustration and getting Parent attention.

- **Make time for fun.** A child coping with autism is still a kid. For both children with autism and their parents, there needs to be more to life than therapy. Schedule playtime when the child is most alert and awake. Figure out ways to have fun together by thinking about the things that make the child smile, laugh, and come out of their shell. The child is likely to enjoy these activities most if they don't seem therapeutic or educational. There are tremendous benefits that result from Parent's enjoyment of child's company and from the child's enjoyment of spending unpreserved time with Parents. Play is an essential part of learning and shouldn't feel like work.

- **Pay attention to child's sensory sensitivities.** Many children with autism are hypersensitive to light, sound, touch, taste, and smell. Other children with autism are "under-sensitive" to sensory stimuli. Figure out what sights, sounds, smells, movements, and tactile sensations trigger Parents kid's "bad" or disruptive behaviors and what elicits a positive response. What does the autistic child find stressful? Calming? Uncomfortable? Enjoyable? If Parents understand what affects the child, Parent shall be better at troubleshooting problems, preventing situations that cause difficulties, and creating successful experiences.

Helping children with autism tip 3: Create a personalized autism treatment plan

With so many different autism treatments available, and it can be tough to figure out which approach is right for Parentsr child. Making things more complicated, Parents may hear different or even conflicting recommendations from parents and doctors. When putting together an autism treatment plan for your child, keep in mind that there is no single treatment that will work for everyone. Each person on the autism spectrum is unique, with different strengths and weaknesses.

The child's treatment should be tailored according to his or her individual needs. Parents know the child best, so it's up to Parents to make sure those needs are being met. Parents can do that by asking Parents the following questions:

A good autism treatment plan will:

- Build on the child's interests.
- Offer a predictable schedule.
- Teach tasks as a series of simple steps.

- Actively engage the child's attention in highly structured activities.
- Provide regular reinforcement of behavior.
- Involve the parents.

Source: *National Institute of Mental Health*

- What are my child's strengths?
- What are my child's weaknesses?
- What behaviors are causing the most problems?
- What important skills is my child lacking?
- How does my child learn best (through seeing, listening, or doing)?
- What does my child enjoy and how can those activities be used in treatment?

Finally, keep in mind that no matter what autism treatment plan is chosen, Parent's involvement is vital to success. Parents can help the child get the most out of treatment by working hand-in-hand with the autism treatment team and following through with the therapy at home.

Choosing autism treatments

When it comes to autism treatment, there are a dizzying variety of therapies and approaches. Some autism therapies focus on reducing problematic behaviors and building communication and social skills, while others deal with sensory integration problems, motor skills, emotional issues, and food sensitivities.

With so many choices, it is extremely important to do Parent's research, talk to autism treatment experts, and ask questions. But keep in mind that Parents don't have to choose just one type of therapy. The goal of autism treatment should be to treat all of child's symptoms and needs. This often requires a combined treatment approach that takes advantage of many different types of therapy.

Common autism treatments include behavior therapy, speech-language therapy, play-based therapy, physical therapy, occupational therapy, and nutritional therapy.

Helping children with autism tip 4: Find help and support

Caring for a child with an autism spectrum disorder can demand a lot of energy and time. There may be days when Parents feel overwhelmed, stressed, or discouraged. Parenting isn't ever easy, and raising a child with special needs is even more challenging. In order to be the best parent Parents can be, it's essential that Parents take care of themselves.

Don't try to do everything on own. Parents don't have to! There are many places that families of autistic kids can turn to for advice, a helping hand, advocacy, and support:

- **Autism support groups** – Joining an autism support group is a great way to meet other families dealing with the same challenges Parents are. Parents can share information, get advice, and lean on each other for emotional support. Just being around others in the same boat and sharing their experience can go a long way toward reducing the isolation many parents feel after receiving a child's autism diagnosis.
- **Respite care** – Every parent needs a break now and again. And for parents coping with the added stress of autism, this is especially true. In respite care, another caregiver takes over temporarily, giving Parents a break for a few hours, days, or even weeks. To find respite care options in your area, see Resources section below.
- **Individual, marital, or family counseling** – If stress, anxiety, or depression is getting to Parents, Parents may want to see a therapist of their own. Therapy is a safe place where Parents can talk honestly about everything their feeling—the good, the bad, and the ugly. Marriage or family therapy can also help Parents work out problems that the challenges of life with an autistic child are causing in their spousal relationship or with other family members.

❖ EMERGING INSTITUTIONS, NEW OPPORTUNITIES: PARENT SUPPORT ORGANISATIONS, CIVIL SOCIETY AND THE LAW

Mission Statements and Core Values

The organization conveys many of its core values and guiding principles on program documents that are published as brochures and reports on organizational activities. A typical AF A brochure is a slim long booklet with a photograph of two children at play on the front cover and a therapist and child in a work-session at the back. Its logo, a smiling child's face in a piece of a jigsaw puzzle is displayed in the lower right hand comers on front and back page: The symbol of the jigsaw puzzle piece is used by many autism organizations world wide. The AFA logo depicts the child's face emerging out of the puzzle piece, symbolizing incorporation into the wider society. Importantly, the face is a smiling one, implying that disability is not a tragedy, that the right to be happy is universal. The booklet has sections that briefly describe autism and the unusual behaviour patterns that enable one to recognize an autistic person. Information about the genesis and development of the National Centre and the services it offers follow, along with a bullet point presentation on "AFA's Pioneering Activities". A fund-raising and membership-recruiting form comprises the last two pages. Attractively designed and presented, the booklet is in the English language. Indeed, most of the publicity and information materials of the organization are in English, thereby limiting their reach to a very small section of the populace. The organization's vision and mission statements prominently printed on the first page of the brochure are as follows:

Vision

A society that views the inter-dependence of people of every ability as valuable and enriching and seeks to provide equal opportunities for all.

Mission

To facilitate a barrier free environment; to empower families of persons with autism and to act as a catalyst for change that will enable persons with autism to live as fully participating members of the community.

The vision of a society based on "interdependence of people of every ability" implies an inherent belief in the equality of all citizens, irrespective of ability or disability and emphasizes the "valuable and enriching" aspects of such interdependence. What is also implied is that the "less equal" members of society also can contribute to this interdependence in a valuable and enriching way, rather that merely being at the receiving end. The vision of "providing equal opportunities for all", although an of used phrase, assumes greater salience when we remember the nature of disability that the organization is associated with. As we have seen earlier, the personhood of the mentally disabled is often undermined or questioned; they are seen as not quite human and hence the question of providing them with "equal opportunities" is rarely taken up seriously. As they are deemed to be "eternal children", in constant need of care and support their rights as individuals tend to be de-emphasized or even violated, as in the well documented case of the hysterectomies carried out on mentally disabled women in Shirur, Maharashtra in 1994 (see Sundar Rajan, 2005). The organization thus envisages a society which grants full personhood to its mentally disabled members, which implies extending all possible opportunities to optimize their potential and live a life of dignity.

In order to realize this vision, the organization conceptualizes its mission in terms of three interrelated dimensions viz., (i) the environment (ii) family (iii) social change,

i) The environment:

It aims to do away with barriers that restrict or prevent the full participation of disabled people in the life of the community, be it physical barriers like 'disabled-unfriendly' architecture or public spaces, or less tangible but discriminatory practices like denying them access to appropriate education, recreation etc. We may cite a highly publicized incident in October 2006, when the autistic son of a South Indian T.V. actor was denied entry on an aircraft, citing an obscure rule. The incident was flashed on live television, and CNN-IBN, a 24 hour news channel ran a series of programmes on the plight of the disabled in Indian society following the incident.

ii) The family:

"Empowering families of persons with autism" is one of the core themes around which the organization is built. Empowerment is sought to be accomplished at multiple levels:

(a) The psychological level, wherein families are counselled to come to terms with the child's disability and better still, acknowledge and embrace it. During the Annual Training Workshop for parents and professionals, Merry Barna usually ends her presentation by narrating the following story. A water-carrier daily carries two pots of water up a hillside. One pot has a crack in it, and, as a result, the water leaks away by the time the water carrier reaches the top of the hill. This goes on for a number of days and months. The cracked pot feels very sad and asks its master to discard it. The master tells the pot to look down at the path they take everyday. Lo and behold! The path is covered with beautiful flowers, whereas on the other side, the side of the intact pot, not a single flower grows. Barna asks parents to see their child as this pot with a crack, which, while unable to retain all the water, nevertheless makes it possible for flowers to blossom in its path. The story usually elicits an emotional response from parents; I have seen many shed tears. Several parents who attended the Annual Workshop reported that it changed their attitude towards their child and fostered acceptance and respect.

The organization also provides families avenues to interact with each other. One of its brochures carries the phrase "Parents are not alone". As reported by several parents, reading this simple line gave them reassurance and alleviated their fears and worries to some extent. The "moment of truth" of being told that one's child will be disabled for life is a life-changing one, as has been discussed in a previous chapter; a profound disposition of order, a "zero-moment", as one parent evocatively put it. In this difficult circumstance, to interact with other families who have gone through the same experiences will be therapeutic. Many families reported that what made them "trust" AFA was the knowledge that its founders and several of its senior therapists were themselves parents of autistic children. By providing a forum for families facing a similar life-changing circumstance, AFA contributes to their empowerment.

Programmes and Activities:

i) Diagnosis and Assessment:

As discussed earlier there is limited awareness and understanding of autism in India, which often goes under-diagnosed or misdiagnosed as mental retardation or psychiatric illnesses. Diagnosis and assessment are therefore a vital part of the services provided by the organization. AF A has so far provided diagnosis and early intervention programmes

for over 1000 children *(Annual Report,* 2005-06: 26). Early and appropriate diagnosis can often make all the difference in future prognosis. It has been noted that AF A has been increasingly receiving referrals from other new professionals as well as parents walking in on their own accord after having read about autism in a magazine or the Internet and finding striking similarities in the presented symptoms.

AFA_ diagnosed a total of *55* children in 2005-06 and carried out functional assessments of 40 children with a large proportion of children in the 2-4 year age grm;tp, i.e., a total of95 children. In the year 2002-03, the number was 45, in 2003-04, 61 and in 2004-05 it was 68. The need for systematic diagnosis of children affected on the Autism Spectrum Disorder made AFA collaborate with the organisation 'Autism Denmark' to develop a Diagnostic Screening Kit. The kit is designed to assist professionals with limited knowledge of autism to detect it early. Prominent hospitals were requested to cooperate in the testing of this kit.

ii) Education:

The 'Open Door School', inaugurated in 1994, was the first of its kind in South Asia which offered specialized services to children with Autism.

There are at present only 20 schools in the country with an average strength of 30 students that cater exclusively to children with autism. (www.autism-india.org) 'Open Door School' numbers are deliberately restricted to 50-60 students at a time so that each child may receive adequate attention, in the absence of large numbers of trained teachers. However, in order to meet the growing demand on its services. AF A has begun strategizing about increasing its capacities for Open Door. The 'Mother Child

Programme' is also a part of the Open Door day programme. In Open Door the children are grouped on the basis of learning and development and have a Specialist Teacher, Junior Teacher and caregiver devoted to a group. Its main objectives to devise, test and tailor new teaching strategies and act as a model and training ground for therapists and parents.

Programmes:

Centre Based Home Management

In this programme for Home Management the parent and a trained AFA therapist design schedules and plans, together. Tailored to each family's individual needs, they provide structures for daily routines and activities that the family carries out with the child at . The plan is implemented at home and the family returns for an update at predetermined intervals of a fortnight or more. The Programme also gives families an opportunity to discuss for solutions to vexing issues of behaviours and learning of daily living skills. 112 families availed of the Home Programme in 2005-06.

Counseling

Counseling is provided to family members for dealing with issues related to the pressures and stress of parenting a child with autism, parenting the sibling of a child with autism, living in a nuclear or a joint family, second child issues, or any other concerns that the families may have. Appropriate coping strategies are discussed and developed with inputs from psychologists and medical professionals.

The Hourly Intervention Programme

More than 348 children availed of this regular ongoing programme in 2005-06, up :from

329 in the previous year. The therapist works one-on-one with the child, one or more times a week with ongoing observation by parents. This Programme is specially helpful

for children who need additional support whether they are preparing for mainstream schools or being schooled at home and specially for ones who are not receiving any other special education inputs.

Parent Support Groups

Social isolation is one of the biggest challenges faced by parents with an autistic child.

To meet this crisis AFA facilitates and supports Parent Support Groups in different parts of the country helping forge links between parents in similar situations. Parental narratives in previous chapters have brought out the importance of support groups for families in this difficult circumstance.

The Mother Child Programme

The MCP, one of AFA's popular programmes reached out to 45 families in 2005-06, as compared to 30 in the previous one. This Programme seeks to maximize the benefits of the time that a mother spends with her child, teaching focused one-on-one intervention tailored individually to each child and taking into account the child's strengths, emerging skills and weakest skill areas. Semi-structured, daily interactions between mothers and their autistic children are conducted in a group setting. The basic goal is for mothers to develop skills that will improve the quality of their interaction with their children, raise their confidence and decrease stress. This, in tum, will have a positive impact on the child's skills.

Vocational and Living Skills Building

With respect to young adults with autism, The task of the organisation becomes more challenging. These young adults have in general received diagnoses very late, and lost out on the benefits of early intervention and appropriate education. The objectives spelt out for the rehabilitation of young adults with autism include the following:

- To impart independence in all living skills like Vocational Skills, Independent Functioning, Leisure Skills, Vocational Behavior, Functional Communication, and Interpersonal Behaviour.

- To train adults in Vocational Skills depending on their interest and abilities that will eventually foster economic independence

- To make the life of adults with autism as regular as possible
- To teach certain social skills that would help them to adjust in their environment
- To run Supported Employment Programmes so as to enable them to lead productive lives
- To inculcate a sense of achievement through the concept and experience of' Work'
- To encourage trainees to pursue hobbies and leisure activities, to help them make independent decisions.
- To ultimately allow for the provision of regular income to trained persons with autism working at *Aadhar* (AFA's Work Skills Centre for adults with autism) as income generating activities are self-sustaining. *(Annual Report,* 2005-06)

The trainees at *Aadhar* are taught Vocational Skills along with Social Skills. They are involved in various activities like stitching, weaving, envelope making and folder making. They also actively assist in office work. They are also taught cooking, painting *diyas* and pots, making *rakhis*, friendship bands, charts, etc. specially during festival seasons and sell their creations at various events at the Centre and other such events conducted by other disability organisations. The trainees niake snacks for breakfast and sell them at the cafeteria in the Centre. They also look after the staffs coffee and tea needs.

The role of a state being a welfare state under Article 12 of the Constitution of India:

In the Constitution of India, the role of the state in the promotion of people's welfare is recognized in unequivocal terms. The Fundamental Rights uphold the equalization of gender, caste and class differences. The Directive Principles take it further. Article 41 of the Directive Principles directs the state "within the limits of (its) economic resources and capacity" to "ensure the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want." Justice Krishna lyer has praised these provisions as reflective of the Indian Constitution's faith in "administrative engineering" and its "comprehensive backing for humanitarian jurisprudence in the area of retardates and handicapped classes" (1980: 193, cited in Sundar Rajan, 2005: 125)

However, as Sundar Raj an points out, directive principles do not have the force of law, and despite the constitutional commitment to creating a welfare state, successive governments have placed limitations on achieving it. She asks, " .. what are the responsibilities acknowledged by the state towards those citizens who have second class status as a result of disability or other forms of deprivation? More crucially, how far is it able, or willing, to fulfil them?" (ibid: 125-126)

Harriss-White (1999) points out that the alleviation of disability in the developing nations in particular is an issue of low priority in "public choice theoretic terms" (1999: 151). The political and economic costs of such welfare measures are high, but their benefits low. Coupled with the apathy of society at large towards these sections of the population, this means that welfare programs require *"ab initio* convincing justifications that the social health of disabled people i~ a necessary precondition not only for economic growth, but also for social welfare." (ibid: 143-144) Out of an estimated four million mentally retarded people requiring services, only eighteen thousand received any through institutions funded by the National Institutes of Mental Health (ibid: 151) "For the mass of disabled people, the state does not exist." (ibid: 19) In the context of autism, we may point out that it was recognized as a disability by the Government of India only in 1999. Therefore, no statistical data is available on its prevalence. As we have earlier mentioned, pnly estimates based upon prevalence rates in other countries can be made, and as per these estimates, the number of autistic people in India is said to range from 2 million to 4 million.

Sundar Rajan (2005) draws our attention ~o the recent trend in welfare administration of the increasing relegation of care functions to non-governmental organizations. "This is offered as a matter of administrative convenience: since bureaucratic functioning is top down, cumbersome, and also, the state seeks to rid itself of low-priority functions, ostensibly those better served by smaller, decentralized mechanisms." (2005: 127) Interestingly, the currents of liberalization that have influenced this process, are also responsible, incidentally and diffusively, for social transformation.

"The expansion of markets has been accompanied by factors that have contributed to interventions in the social sector; among them, the increase of funding from foreign agencies both to government and to NGOs working in these areas; .. the recent establishment by the United Nations of human rights agendas covering the disabled and the mentally retarded; the presence and scrutiny of their observance by international as well as national human rights organizations; and the diffusive but real influence of the gaze and the example of the West." (ibid: 128)

There is also an increasing middle-class sensitization and visible popular support for issues that had earlier engaged only activists in movements, which is in marked contrast to the "pervasive public indifference to larger social issues said to characterize Indian society." (ibid: 129)

However, the issue of "what happens to the child after the parents are gone?" is as yet unaddressed, and a source of extreme stress and worry to all the parents spoken to during the course of the study. We may once again emphasis that in the Indian context, it is the family that is automatically deemed responsible for looking after disabled members, obtaining whatever resources and facilities they can for the care of the disabled person, and in the absence of such facilities, managing as best as they can.

While this study focuses on mental disability within an urban middle-class context, the plight of countless individuals condemned to live a sub-human existence due to poverty and ignorance can well be imagined. State-run residential institutions for the mentally disabled are woefully inadequate, lacking ·infrastructure, trained personnel and appropriate attitudinal orientation. Privately run residential institutions are few and those that exist are either prohibitively expensive or else lack ·quality-control mechanisms and monitoring. Given these constraints, an effective and culturally appropriate method of ensuring life long care and support to affected individuals could be through a system of community care or group homes managed co-operatively by families with adequate support from the community and state. While such measures have yet to be initiated by civil society players, the problem of adult autistic people being cared for by aged parents or siblings is becoming more and more acute. With traditional family networks dwindling, family size becoming smaller, migration (national and international), the almost automatic assumption of care-giving · responsibilities being taken over by siblings and. the extended family is being challenged. In this context it becomes important to study the legal provisions in place for the continued maintenance and care of individuals with mental disabilities including autism.

MENTAL DISABILITY AND THE LAW

This section draws upon information provided in the Training Modules prepared by the Human Rights Law Network pertaining to the legal provisions for persons with disabilities. Laws reflect the thinking and understanding of a society at a particular time in history. Before 1995, there was no comprehensive law in India outlining the rights of persons with disability in our country. While physical disabilities resulting from injury in the workplace were and still are covered under Acts such as the Workman's Compensation Act or the Employees State Insurance Act, mental disabilities were subsumed under the Indian Lunacy Act. The act made no distinction between the mentally disabled and the mentally ill and dealt with the institutionalization of people with mental retardation and mental illness. It was repealed and replaced in 1987 with the Mental Health Act. In an effort to separate the concerns of people with mental retardation and mental illness, the Mental Health Act deals with the institutionalization and guardianship of people with mental illness. While it addresses the issues of establishment of psychiatric hospitals, admission of affected individuals in such facilities and appointment of guardians and managers of property of such persons, it fails to address such issues as education, employment, social security or any kind of affirmative action, reflecting societal perceptions of such individuals as "unfortunates" who need charity, rather than opportunities to lead a fulfilling life.

The Asia-Pacific Decade of Disabled Persons launched in 1993 adopted the proclamation on Full Participation and Equality of Persons with Disability in the Asia Pacific Region. Many countries in the region framed laws that specifically supported the rights of persons with disabilities. In India too, much debate and discussion led to the framing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which was the first such comprehensive law for the rights of the disabled. The PWD Act outlines the rights of disabled people and the responsibilities and obligations placed on the Government of India, State Governments and other local governmental bodies for the realization of these rights. For the first time the law clarified who a person with disability is in the country. The Act recognizes the following categories of disability:

1. Blindness

2. Low Vision

3. Leprosy-cured

4. Hearing Impairment

5. Loco motor Disability

6. Mental Retardation

7. Mental Illness

For the first time, people with mental illness were recognized as persons with disabilities and Q.olders of rights under the law, not just as people requiring medical care and institutionalization. However, the law did not take into account the very special needs of a group of people with severe disabilities like Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. Even though Mental Retardation and Cerebral Palsy were included in the PWD Act, provisions for their long-term care were seen as inadequate by parent groups. As for Autism and Multiple Disabilities, they did not find even a mention, perhaps because of the relative paucity of information available and the fact that Autism routinely tended to be mistaken for either mental retardation or mental illness. Parents' groups and disability activists felt that the law did not address the issues of their protection and support once their parents were no longer there to look after them. As a result of the strong advocacy of parents' groups across the country (including AFA), The National Trust Act came into being in 1999. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 envisages the setting up of a Trust which will be managed by a Board of Trustees. The Board will be the body that decides matters related to the implementation of the law.

Aims and Objectives of the Trust

a) To enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
b) To strengthen facilities to provide support to persons with disability to live within their own families;
c) To extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability;
d) To deal with problems of persons with disability who do not have family support;
e) To promote measures for the care and protection of persons with disability in the event of death of their parent or guardian;
f) To evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection;
g) To facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability; and
h) To do any other act which is incidental to the aforesaid objects.

Free U.S. government services for children with autism For services for children with autism in other countries

See links in Resources & References section below.

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.

Early intervention services (birth through age two)

Infants and toddlers through the age of two receive assistance through the Early Intervention program. In order to qualify, the child must first undergo a free evaluation. If the assessment reveals a developmental problem, Parents will work with early intervention treatment providers to develop an Individualized Family Service Plan (IFSP). An IFSP describes the child's needs and the specific services he or she will receive.

For autism, an IFSP would include a variety of behavior, physical, speech, and play therapies. It would focus on preparing autistic kids for the eventual transition to school. Early intervention services are typically conducted in the home or at a child care center.

To locate local early intervention services for the child, ask to the pediatrician for a referral or use the resources listed in the box to the right.

Special education services (age three and older)

Children over the age of three receive assistance through school-based programs. As with early intervention, special education services are tailored to the child's individual needs. Children with autism spectrum disorders are often placed with other developmentally-delayed kids in small groups where they can receive more individual attention and specialized instruction. However, depending on their abilities, they may also spend at least part of the school day in a regular classroom. The goal is to place kids in the least restrictive environment possible where they are still able to learn.

If parents would like to pursue special education services, their local school system will first need to evaluate the child. Based on this assessment, an Individualized Education Plan (IEP) will be created. An IEP outlines the educational goals for the child for the school year. Additionally, it describes the special services or aids the school will provide your child in order to meet those goals.

Know your child's rights provided under various schemes and laws:

Children on account of their tender age and immature mind need special care and protection. They have certain special rights and legal entitlements that are being acknowledged nationally and internationally. The constitution of India recognized the rights of children for the first time and included several articles dealing with their liberty, livelihood, and development of childhood, non-discrimination in educational spheres, compulsory and free education and prohibition of their employment in factories, mines and hazardous industries. Socially and physically children are the weakest element of the society. They are not responsible for many of the cases and do not deserve to suffer. They have no say in any of the matters of evils like war or external debt. It has been rightly stated in the 1924 declaration of rights of the child (declaration of Geneva) that has now been used for all child causes "mankind owes to the chills the best it has to give".

As the parent of an autistic child, Parents have a legal right to:

- Be involved in developing the child's IEP from start to finish.
- Disagree with the school system's recommendations.
- Seek an outside evaluation for the child.
- Invite anyone Parents want—from a relative to the child's doctor—to be on the IEP team.
- Request an IEP meeting at any time if Parents feel the child's needs are not being met.
- Free or low-cost legal representation if Parents can't come to an agreement with the school.