

Parent and Teacher Guidebook for Autism

2nd Edition

Dr. Alok Sharma

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Autism Child Development Centre (ACDC)



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2nd Edition

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*This book is dedicated to
all the courageous and loving
Mummies and Papas
of the special children with autism.*



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In summary: He is a Neurosurgeon, Medical Teacher and Scientist who is attempting to combine the best of science, medicine and humanity to make a difference to the lives of people who are suffering from neurological disorders.

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Ms. Akshata Shetty is a Clinical Psychologist and Head of Autism Child Development Centre at NeuroGen Brain and Spine Institute, Navi Mumbai. She has completed her masters in clinical psychology and has an experience of 5 years. Her clinical expertise and interest lies in the field of pediatrics and especially in Autism Spectrum Disorders. She specializes in conducting psychometric tests in pediatrics and adult patients. She is also working on the behavioural issues displayed by children with Autism. She has 7 scientific publications to her name in the field of stem cell therapy and has written chapters in various books. She was also the Organising Secretary of the International Conference of Autism, Cerebral Palsy and Neurodevelopmental disorders which was held in 2015 at Renaissance, Mumbai.



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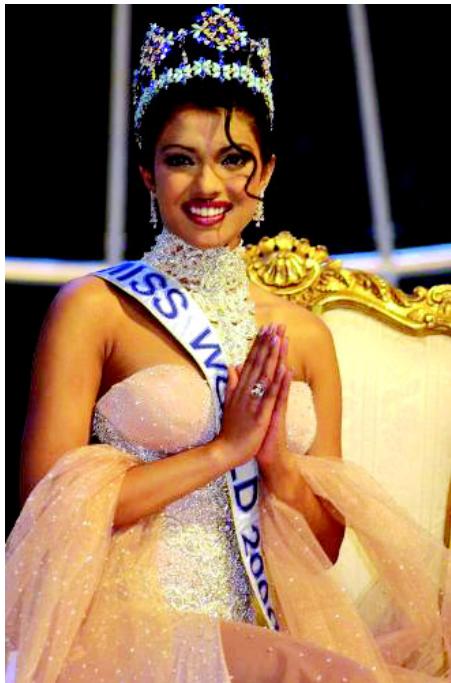
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Foreword for 1st Edition



Priyanka Chopra :
Miss World -2000



Priyanka Chopra :
As Jhilmil in 'BARFI!'

Priyanka Chopra

Date: 24th January, 2013.

To,

The parents & Teacher of Children with Autism.

Recently I played the character of Jhilmil who was a character that suffered from autism. When we were researching what we wanted Jhilmil to be and how she would be, she turned into that person by meeting and speaking to a lot of people. That is how she emerged. There is no real reference point to how Jhilmil was. We have not derived her from any reference of any character.

Because autism's range and the range of symptoms are so huge, it can be anything. That is what exactly she is. She has an incredible childlike innocent quality to her.

Did you know that a child with high functioning autism may have a normal or high I.Q., be able to attend a regular school and hold a job later in life. However, this person may have difficulty expressing himself and may not know how to mix with other people.

Children with autism are creators, they live in their own world which is very different from ours, yet they seem so self sufficient whereas we struggle to grapple with our own surroundings. This is what interested me and got me to read and learn more about them.

This book is a step in that direction. We as parents need to understand what our child is going through and help nurture his interest by trying to understand their worlds. Its an effort to bridge the gap by helping us decipher them and help them to become a part of our society.

A guidebook like this is invaluable for all the people and especially parents who deal with autism on a regular basis. I only wish that had such a book been available earlier, Jhilmil would have been understood a whole lot better.



Priyanka Chopra



"To believe that, what has not occurred in history will not occur at all, is to argue disbelief in the dignity of man."

– **Mahatma Gandhi**



Security is mostly a superstition. It does not exist in nature nor do children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure. Life is either a daring adventure or nothing"

– **Hellen Keller**

"The present is the only time when we can work and achieve, gain and gather. In the past we can now do nothing. In the future again we can accomplish nothing. In the 'dead' moments of the past and in the 'unborn' moments of the future we can never act. These 'living' movements are the only fields to be hammered at and wherein are all the glories of life, all the gains in existence.

Time never stops. It is fleeting. The now is the only auspicious occasion to initiate our new plans. Delays are dangerous, useless and barren. Today is the only day to attempt any great and worthy purpose. Opportunity comes to all of us. The diligent catch hold of it. The foolish let it pass. Therefore let us be smart and awake to recognize our opportunity to serve and while it is within our reach let us seize it and make it yield to us the results we demand.

What we have is a gift from God. But what we do with that is our own gift to God. Make your life a total gift to God."

– Swami Chinmayananda

"This is the true joy in life, the being used for a purpose recognized by yourself as a mighty one. The being a force of nature rather than a selfish feverish little clod of aliments and grievances complaining that the world will not devote itself to making you happy. I am of the opinion that my life belongs to the whole community and as long as I live its my privilege to do for it whatever I can. I want to be thoroughly used up when I die for the harder I work the more I live. I rejoice in life for its own sake. Life is no brief candle to me but a splendid torch that I have got hold of for the moment and I want to make it burn as brightly as possible before handing it over to future generations."

– George Bernard Shaw

Inspiration



Dr. Temple Grandin

Grandin was diagnosed with autism at the age of 2 years. She began to speak at the age of 4 after extensive speech therapy but her social interaction remained poor. School years were difficult for her as other students teased Grandin for her verbal tics. Despite these, she succeeded academically and received a degree in psychology followed by a master's and doctor's degree in animal science.

Today, Dr. Temple Grandin is a Professor at Colorado State University and is a professional designer of humane livestock facilities. She gives credit to "autism" for her achievements. She says she would never have been so attuned to animal sensibilities or the fine points of agricultural engineering without the distinctive vision and hypersensitivity that comes with autism. She is an active autism activist and she was listed in the Time 100 list (2010) of the 100 most influential people in the world.

In her autobiography, "Thinking in Pictures: My Life With Autism," Temple Grandin says that she values "positive, measurable results more than emotion." Grandin was portrayed in Oliver Sacks's (1995) book "An Anthropologist on Mars" and the HBO movie "Temple Grandin". The movie honors Temple Grandin's priorities, tearful setbacks and joyous breakthroughs. Her life's story and writings are truly inspirational and provide an insight into the intangible worlds of individual's with autism.

Preface to 1st Edition

Autism is one of the most unrecognized and neglected epidemics of our time and its an epidemic whose incidence is increasing significantly. Since for all these years there was no definitive medical or surgical treatment available for autism, doctors found themselves limited to making the diagnosis and giving symptomatic relief to symptoms like epilepsy and behavioral problems. It was therefore left to the special educators and the rehabilitation therapists to do whatever they could for these children.

This therefore put the entire onus of treating and managing these children on the parents. Having a child with autism in the family has always been a devastating experience for the family. Whilst on one hand the children looked healthy like other children, the fact was that their behaviors and actions never let them fully integrate into the mainstream life. Their hyperactivity and their sometimes aggressive behavior made them difficult to handle. They were also not easily accepted by other children of their age group.

Parents of children with autism (especially the mothers) have to put almost every aspect of the rest of their lives on hold as they struggle with the intensely challenging task of looking after the child with autism. Looking after these children involves hard physical strenuous work, lots of time, a very positive attitude and a spiritual acceptance of this difficult reality. The lack of understanding of society to the special needs and requirements of these children made things worse. They are often called all kinds of names and treated with lack of caring and understanding. Some of their uncontrolled behavior could potentially cause hurt to themselves or others, so they can never be left alone. Parents of children with autism feel very alone in this world. It is almost as if there is no one who will understand what they are going through and the sacrifices that make every day just to see that their child is well.

The task for special educators is not an easy one too. They have to work against very difficult odds, since getting children with autism to co-operate with educational activities is not easy. The learning process is slow, their communication skills are weak and sometimes their behavioral issues can make working with them very challenging. These problems also make the jobs of occupational therapists, speech therapists, psychologists and counsellors very demanding.

We therefore realized that the only support structure that children with autism had were their parents, teachers and rehabilitation therapists. It is our belief that well informed and empowered parents, teachers and therapists would be able to make the biggest difference to the lives of children with autism. In this book, we have addressed all aspects of autism from the possible causes to the different forms of therapies and treatments. We salute the courage, perseverance and efforts that they put in on a day to day basis and do hope that this book will provide them with the information they need to help these children.

Children with Autism are very special indeed. They live in their own world. They have a purity of thought and action that we sometimes wish the rest of the world had too. Their needs and requirements are limited. They never lie. They cannot pretend. They do not try to be who they are not. They do not know what it is like to cheat someone. There is a wonderful simplicity and genuineness to them and they can be very loving and caring. Their smiles and laughter is so real. Yes, they are very very special. Unfortunately, they cannot completely look after themselves and need to be looked after. If there was some way in which we could make them functionally independent then we would have achieved a lot.

This is where a new hope has appeared in the medical world with the most recent availability of Stem cell therapy. Recent imaging studies have shown that there are some parts of the brain of the child with autism that are not functioning properly. Stem cell therapy has shown to correct and repair these damaged parts of the brain. This has opened up a completely new line of treatment for children with autism. What the parents had been told by doctors all these years that nothing can be done, is no longer valid. There is a treatment available and that treatment is not in the distant future, it is available right now. It is safe and it is effective. Children with autism show many improvements with this therapy.

At this point I just have to share something about Shantanu, one of our earliest Stem cell therapy recepiants (whose picture is there on the cover of this book). During the last week of this book's preparation, our team went to visit Shantanu at his home to take pictures and saw something incredible. Shantanu was actually teaching and taking tuitions for a deaf child. We were all so emotionally moved. A child who used to go to a special school himself, had now improved so much after Stem cell therapy that not only did he not need to go a special school anymore, but he was now actually teaching and helping other children with special needs.

We do understand that since this is a new form of therapy, it is natural that as parents you will be concerned about various aspects of the treatment particularly its safety and efficacy. In this book we have given you all the information that you may need to understand Stem cell therapy and all its aspects, in a simple and easy to read manner. More detailed information is available in our other books which are shown on the back cover.

We wish you all happy reading and do hope that with all the information that we have so painstakingly assimilated and put together, you will be able to make a positive difference to the lives of your very special children with autism.

Preface to 2nd Edition

It's been two years since we wrote and published the 1st edition of this book. Since then a whole lot has happened in the medical treatment of Autism. There is now a greater aggressiveness in attempting to reverse the limitations these children have. Apart from the conventional therapies such as occupational therapy, psychological therapy and speech therapy there are now a whole lot of new therapies such as aquatic therapy, art therapy, music therapy and dance therapy etc that are all contributing to the quality of life of children with autism.

The biggest break-through in autism however has been a better understanding of the neurobiological changes that occur in autism and a correction of these with Stem Cell Therapy. Our own clinical results of the role of Stem Cell Therapy in Autism were published in the journal "Stem Cell International" in July 2013. This was the world's first paper that clearly documented the safety and efficacy of Cell Therapy in Autism. Our first scientific paper along with the subsequent six papers very clearly shatters the myth that autism cannot be treated or reversed. The significant clinical improvements as well as the definitive objective improvements in PET CT scans that we have recorded are clear evidence of enormous potential Stem Cell Therapy has in the treatment of Autism. Of course much more work needs to be done before Stem Cell Therapy becomes a Standard of Care. However Stem Cell Therapy is definitely now "An idea whose time has come". Other newer treatment options such as Hyperbaric therapy, Neurofeedback, newer medications etc when combined with Stem Cell Therapy are likely to dramatically improve the responsiveness of the children with Autism to the Conventional Rehabilitation Therapies.

Eventually it will be a combination of Medical, Regenerative and Rehabilitation therapies that will get the children of Autism back to Independent living. There is a definitive 'Shift in the Wind' as hopelessness is giving way to hope and as modern developments in science and medicines are finally helping us to win our battle with Autism.

Despite all this at the end of the day it's the parents who have to manage the day to day lives and difficulties of looking after these children. We believe that well informed parents can make well informed judgements on what is best for their children. This book is intended for the specific purpose of empowering and informing the parents of children with Autism. We wish you all the best.

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INTRODUCTION

Introduction

What is Autism?

A dysfunction in the neurological network of the brain manifests into the spectrum of autism. It is a neuro-developmental disorder which leads to difficulties in speech, communication, social interaction, behavior, sensory issue and thinking ability. Children with autism have compromised mental capacities due to subnormal functioning of some areas of their brain. Despite normal physical appearance, their daily functioning is affected. Children with autism have special needs that must be catered to differently. The diagnosis of autism is usually made in early childhood and despite extensive research, the causes of autism haven't been definitively defined as yet.

Historical Background

In 1943, Dr. Leo Kanner, a well known psychiatrist in his classic paper "Autistic Disturbances of Affective Contact", describes his observations of a child in these words - "He seems to be self-satisfied. He has no apparent affection when petted. He does not observe the fact that anyone comes or goes, and never seems glad to see father or mother or any playmate. He seems almost to draw into his shell and live within himself." Kanner coined the word "Autism" to describe such children. The term autism is derived from the Greek word autos, meaning "self". Dr. Kanner suspected that these children were often misdiagnosed with mental retardation or childhood schizophrenia. Thus he put forth a triad of impairment in the domains of social interaction, speech and communication and imagination. He noted that these children did not display the usual motivation towards social and affective interaction with others; for example; they seemed to be living in their own world. Their communication was manifested either by absence of speech or they had odd nature of speech for example; echolalia (repeating after others words or sentences). They



Figure A : Dr. Leo Kanner

would either be over sensitive to the environmental stimuli such as particular sounds, change in routine or environment.

In the 1960's and 70's, Dr. Bernard Rimland, the father of an autistic child and founder of the Autism Society of America and the Autism Research Institute, helped the medical community understand that autism was a biological disorder. His writings steered the way towards our present understanding of this neurological condition.

Reaching Out...

The birth of a child is the most joyous phase of life for the parents. Especially when you have been told by your doctor that your child is healthy and normal. You would be dreaming big for your child and leaving no stone unturned to give him a good and healthy life. It is a happy experience to see your child crawling the first time, sitting and standing. However, gradually you would notice that he avoids making eye contact, his speech starts regressing, and he wouldn't give social smile and keeps running or jumping around. You may have ignored these few signs initially or have been told by the elders in the family that "may be the child's development is a bit delayed but it's normal". However eventually you would have noticed that your child is moving into an empty shell and the warning bells may have started ringing in your head. Then you must have visited to your pediatrician who diagnosed your child with Autism and explained to you that there is "NO CURE" for Autism. This revelation is shocking and initially you deny it and consult other doctors for answers. Slowly the fact that your child has Autism would have sunken into you and his autistic features might be full blown and difficult to manage.

Often, a diagnosis of "Autism" is associated with a strong emotional reaction from the

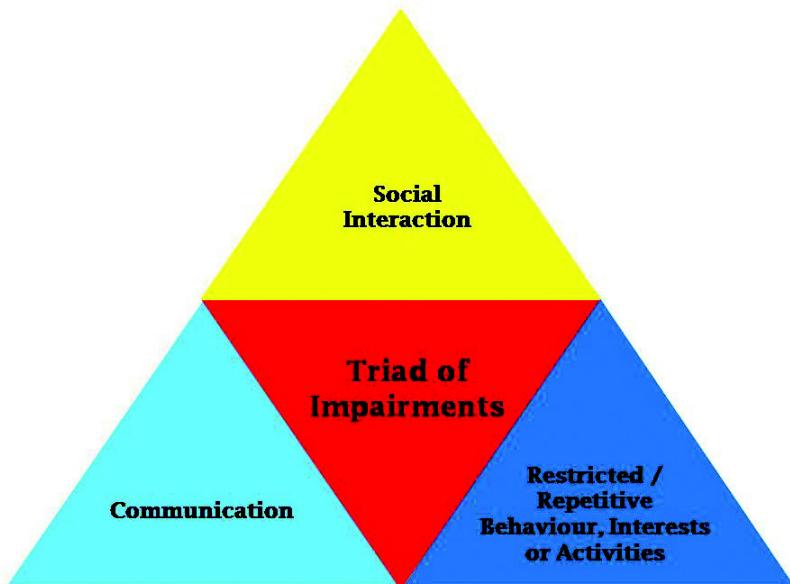


Figure B - Triad of Impairments

parents and family members. The apprehension leads to several questions in their minds.

- What does it mean?
- What is the cause?
- Where do I start?
- Can it be treated?
- How will I take care of my child?
- What would be the future of my child?

Those of us dealing with these children are conscious of the increasing need for guidance and awareness about autism and its management. Handling children with autism is a complex challenge. This book is written with the belief that if the primary caregivers (parents and special educators) have a clear understanding of the disorder and the available treatment options including the more recent scientific and medical developments, then they will be in a better position to manage these children. There is a lot of scattered information available about autism on the internet and in various scientific and press publications, addressing different groups of individuals involved with autism. This book is a concise assimilation of all this valuable information along with our own personal experiences that is specifically relevant to parents and special educators. This book is written with an intention to provide simple and easy-to-follow text with clear illustrations. We hope to provide all the necessary information about the condition and its treatment, help you come to terms with the disease and cope with the challenges. This book is an attempt to familiarize the parents and caregivers with the most recent treatment options and therapies which may bring a new ray of hope and improve their quality of life.

Reference:

1. Leo Kanner. 'Autistic Disturbances of Affective contact' Nervous child, 1943.



SECTION A

1. About Autism

Autism is defined as a complex neurodevelopmental disability that typically appears during the first three years of life and impacts development in the areas of social interaction, communication skills and behavior. Autism is a result of highly complex interaction between the genes, brain and behavior through the developmental period. Autism is associated with early malfunction of a few structures of brain which are involved in processing social information. Despite the lack of specialized neural systems, children with autism continue to survive in an attempt to fit into the highly social environment.

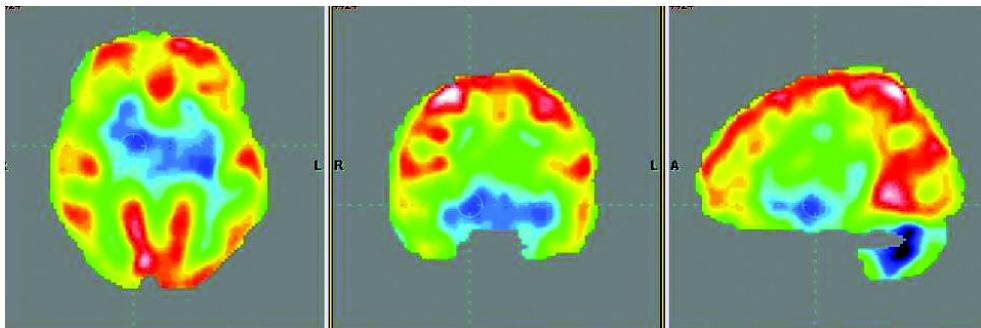


Figure 1.1: Pre PET Brain Scan of a child diagnosed with Autism

Autism... The Worldwide scenario

Autism is found throughout the world, in families from all economic, social, and racial backgrounds. As parents you may often wonder as to why only your child has the disorder. It is therefore important for all of us to recognize that autism is not a rare condition but a common disorder all over the world. Studies in Asia and Europe have identified an average prevalence of about 1% while South Korea was reported with a prevalence of 2.6%. Not only are the present numbers alarming, but they are also progressively increasing over time. The steep increase in numbers could be attributed to several factors like the lifestyle changes, environmental/ climatic factors, changes in

social structure etc. Often these children are incorrectly diagnosed or remain undiagnosed and hence, the actual numbers are still not clear. Autism spectrum disorders are four to five times more common in boys than in girls. However, girls with this disorder have greater chances of having severe mental retardation as compared to boys.

The American scenario...

According to the estimates from the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 68 children in the USA have been identified with Autism Spectrum Disorder, which is a prevalence rate of 1.14%. A study in the United States shows the increasing prevalence over a span of 37 years. From one in 5,000 the prevalence has increased to a current one in 88 persons. More than 7, 00,000 lakhs Americans live with an autism spectrum disorder. (Buescher et al., 2014).

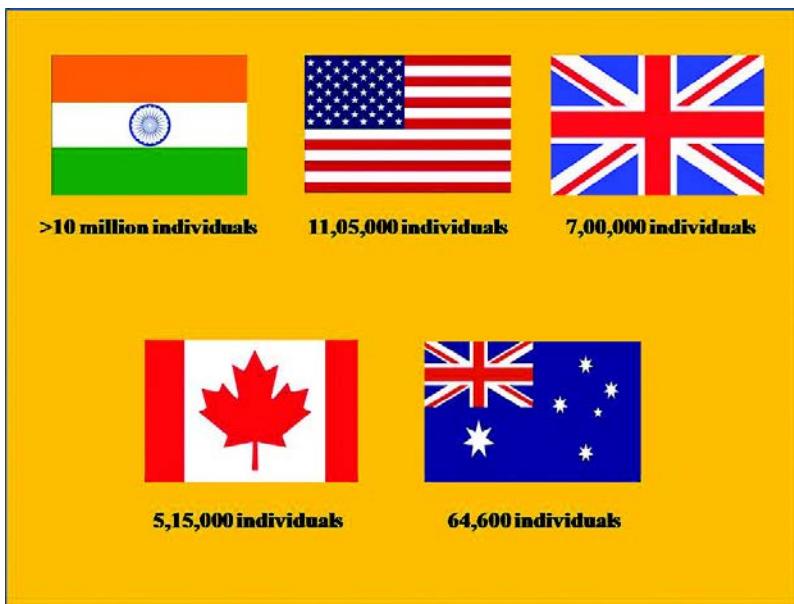


Figure 1.2 - Worldwide Prevalence

The Indian scenario...

According to the Autism Society of India, approximately one in every 250 persons (i.e., a total of nearly 40,00,000 individuals) have autism in India. We believe that the incidence has shown a significant increase over the last several years. The greater focus on autism

is highlighted by the fact that over the last decade four bollywood blockbuster movies starring superstars like Priyanka Chopra, Shahrukh Khan, Hrithik Roshan and Amir Khan have been filmed with Autism or some related disorder (learning disability, mental retardation) as their central theme. These films like 'BARFI!', 'MY NAME IS KHAN', and 'KOI... MIL GAYA' and 'TAARE ZAMEEN PAR' have sensitized the masses and increased awareness among them to some extent. Several medical institutions, research centers, national forums, associations and non-profit organizations have actively taken up the cause. Yet, there still remains a strong need for additional actionable initiatives from the government authorities and the medical fraternity to further the cause of "Autism" and newer treatment options.



Figure 1.3 - Famous Indian movies highlighting Autism and related disorders

What does Autism Spectrum Disorder comprise of?

The term "spectrum" refers to a wide range of symptoms, skills, and levels of impairment or disability that children with ASD can have. Some children are mildly impaired by their symptoms, while others are severely affected.

According to the Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV- TR) there were five disorders classified under the umbrella term officially known as Pervasive Developmental Disorder (PDD) which are Autistic disorder, Asperger's Syndrome, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS),

Rett's Syndrome and Childhood Disintegrative Disorder. However, according to the latest edition of the Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM - V) a diagnosis of ASD now includes several conditions that used to be once diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's syndrome. These conditions are now all called autism spectrum disorder.

The diagnostic criteria for ASD according to DSM V:

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
 - 1. Deficits in social-emotional reciprocity, for example, reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 - 2. Deficits in nonverbal communicative behaviors which are used for social interaction, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 - 3. Deficits in developing, maintaining, and understanding relationships, for example, difficulty in adjusting to behaviors to suit various social contexts; sharing imaginative play or in making friends.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
 - 1. Stereotyped or repetitive motor movements, use of objects, or speech for example, simple motor stereotypies, lining up toys or flipping objects or echolalia.
 - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior, for example, extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day.
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus for example, strong attachment or preoccupation with unusual objects or excessively restricted.
 - 4. Hyper or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment, for example, apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.
- C. Symptoms must be present in the early developmental period (However, the symptoms may not fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

- E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur. To make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

The diagnostic criteria for ASD according to DSM - IV - TR:

Prior to the introduction of DSM V in 2013 individuals with autism were diagnosed as per the DSM IV TR criteria which was as follows:

a. Autistic disorder

Also called "classic autism", autistic disorder is what people relate to when they hear the word "autism". Epidemiological studies suggest rates of 2-5 cases per 10,000 individuals. Rates of the disorder are four to five times higher in males than in females. Typically, onset is seen prior to 3 years of age. People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability (low Intelligence Quotient). In about one-third of cases, some degree of partial independence is possible.

b. Asperger's syndrome

An Austrian pediatrician Hans Asperger, out of interest in special education, described four children between six and eleven years of age who had the inability to socially integrate into groups despite seemingly adequate cognitive and verbal skills. Named after him, Asperger's Syndrome is a developmental disorder which is more common in males but may be under diagnosed in females. The speech and language development is near normal with good understanding, as compared to children with autism. This disorder falls under the autism spectrum disorder, where the distinguishing feature is the child's obsessive interest in a single object or a topic. For example encyclopedic knowledge, astronomy or geography. These children have poor social skills and their areas of interest are very narrow, due to which they often have difficulty initiating conversations and are often isolated. This is because of impairment in the social use of language. They may also have delayed motor development and poor co-ordination, for example catching a ball or playing outdoor games, walking, marching etc.

Asperger's Syndrome does not affect the life expectancy of a person. Adults with Asperger's may be able to work successfully; however, they may continue to need encouragement and moral support to maintain an independent life.

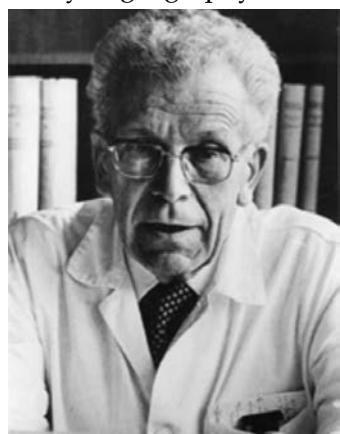


Figure 1.4: Hans Asperger

c. Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS)

The term Pervasive Developmental Disorder-Not Otherwise Specified is used for children or adults who fall under the autism spectrum disorder but who do not fully meet the criteria for autistic disorder. PDD-NOS have one distinct symptom pattern, namely impairments in social communication, without significant repetitive and stereotyped behaviours (RSB). Compared to autistic disorder and Asperger's disorder, there is more severe and circumscribed social communication difficulties. They have fewer non-social features of autism, such as sensory, feeding and visuo-spatial problems. A person may have significant autistic symptoms in one core area such as social skills, but mild or no symptoms in another core area such as behavioral repertoire i.e. may not show repetitive patterns of behavior. PDD - NOS has 3 sub-groups. They are as follows:

- A high functioning sub group of individuals (around 25 percent) whose symptoms are largely overlapping with that of Asperger's Syndrome, but who differ in terms of having poor language development and mild cognitive impairment. Asperger's syndrome however does not involve speech delay or cognitive impairment.
- The second group of individuals (around 25 percent) whose symptoms closely resemble those of autistic disorder, but do not fully meet the diagnostic signs and symptoms.
- The third group of individuals (around 50 percent), who meet the diagnostic criteria for autistic disorder, but whose stereotypical and repetitive behaviors are mildly noticeable.

d. Rett's syndrome

Dr. Andreas Rett, an Austrian neurologist first described this syndrome in 1966. Rett's syndrome occurs in 1 out of every 10,000 to 15, 000 people, which suggests that this condition is quite rare. It primarily affects females. These children have normal developmental milestones between 6 and 18 months. However, thereafter the child's mental and social development which had been achieved, start regressing. This regression of the achieved development is the classic feature of Rett's Syndrome. The developmental regression seems to increase during the early years of schooling.

The characteristic features of Rett's Syndrome are:

- Slowed head growth after 6 months of age
- Absence of speech and loss of communication
- Lack of interest in other people, toys or their surroundings



Figure 1.5: Dr. Andreas Rett

- Excessive pre-occupation with abnormal hand movements like hand wringing, twisting, squeezing, clapping, tapping, etc.
- Coarse, jerky movements of the trunk and limbs, stiff legged, broad based gait and swaying movements of the shoulder when walking
- Maintenance of eye contact is normal or sometimes very intense, but unusual eye movements such as blinking or winking (closing one eye at a time) are seen
- Facial grimacing (unwanted twisting or distorting movements of face), teeth grinding,
- Breathing problems like breath holding, breathing rapidly or forceful exhalation
- Abnormal behaviors like long bouts of laughter, hand licking, screaming without any reason, etc.
- Seizures which may vary from child to child (some may have periodic muscle spasms whereas others may have full-blown epilepsy)
- Scoliosis (sideward bending of the spine or back bone) which appears by the age of 8 to 11 years
- Constipation

Rett's syndrome is commonly divided into four stages.

- **Stage I:** Very often the signs are overlooked during the first stage, which starts when the infant is between 6 months to 18 months of age. At this stage infants usually start losing their interest in toys or may show less eye contact. They may also have developmental delays in crawling and sitting.
- **Stage II:** This stage starts between 1 and 4 years of age and eventually these children lose the ability to speak or use their hand purposefully. At this stage, the progression starts with children repetitively moving their hands, holding their breath or screaming for no apparent reason. It often becomes difficult for them to go from one place to another, on their own.
- **Stage III:** This stage starts between ages 2 to 10 years and can last for several years thereafter. During this stage, children usually cry less and become less irritable. Display of eye contact and the use of eyes and hands to communicate, generally improve during this stage. Many people with Rett's syndrome remain in this stage for the rest of their lives.
- **Stage IV:** This last stage is marked by reduced mobility, muscle weakness and scoliosis. Understanding, communication and hand skills generally don't decline further during this stage. In fact, repetitive hand movements may decrease. Although sudden death can occur, most people with Rett's syndrome live into their 40s or 50s. They usually need care and assistance throughout their lives.

e. Childhood disintegrative disorder

Childhood disintegrative disorder is a type of Autism spectrum disorder. The

average onset of this disorder is between the ages three and four years, until which the child is able to achieve age appropriate skills in communication and social relationships. The distinguishing feature of CDD from Rett's syndrome is that CDD takes a bit longer to be seen, usually until 2 years of age and maybe not till age 10. There is the biggest difference which is the dramatic decrease in the growth of the head seen in Rett's which is not expressed in CDD. According to many surveys, fewer than 2 children per 10,000 are diagnosed as having childhood disintegrative disorder. This suggests that this condition is quite a rare form. This disorder is more common in males than in females. Characteristic Features of Childhood Disintegrative Disorder are:

- Loss of Vocabulary (words of a language)
- Loss of bladder and bowel control
- History of seizures
- Low Intelligence Quotient

	AUTISM	ASPERGERS	PDD-NOS	RETT'S <i>(regression of gross motor function, physical features prominent)</i>	CDD
Social relationship and reciprocity	Difficulty in understanding and responding to people according to the situation and place. Cannot interact with peer group and participate in socially acceptable conversations	Inability to integrate socially with people, despite of adequate language in speech	Presence of severe problems with social interaction, understanding social relationships, and reciprocating to people in the social environment		
Emotional responsiveness	Exhibits extreme emotional responses, outbursts.			Bouts of laughter, screaming	
Speech language and communication	Speech is affected since the beginning, both receptive and expressive communication is hampered		Have delayed speech, and when language develops, it often is not functional.	Regression leading to absence of speech and thus loss of communication	Loss of speech, overall regression seen in the later ages, as compared to Rett's

	AUTISM	ASPERGERS	PDD-NOS	RETT'S <i>(regression of gross motor function, physical features prominent)</i>	CDD
Behavior patterns	Shows repetitive behavioral patterns like rocking, hand flapping, also repetitive speech	Obsessive interest in a typical object or a topic	Minimal or no repetitive behavioral patterns	Excessively preoccupied with abnormal hand movements like hand wringing, squeezing, etc.	
Sensory aspects	Is aversive to certain sensations, or on the contrary seeks excessive sensations			Teeth grinding	
Cognitive component	Intelligence is affected in certain cases				Low intelligent quotient

There are subtle differences between the features and degrees of severity within these five conditions, but the treatment and educational needs of children with any of these disorders will be very similar.

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2. Causes of Autism

What causes Autism?

When parents of children with autism come to us for consultation and advice, the first thing they ask us is

- How did our child develop autism?
- My child was hale and healthy and had even started to speak a few words. Then, what happened suddenly?"
- Is autism acquired?
- Does it happen after the child is born?
- Could it have been prevented?
- Is it genetic?
- Can the other children also have autism?
- Has it come from "us", the parents?

Do we yet have clear cut answers for these questions? Some yes and some no!!

Let us explore what is known and what is still being understood. For a fact, the understanding of the "what", "why" and "how" of autism is still incomplete.

The number of people known to have autism has increased dramatically since the 1980s, partly due to changes in diagnostic practice and more importantly due to increased awareness about the disorder. It is however not known whether prevalence has increased as well. By 2010, the CDC's estimate for ASD prevalence was stated at 14.7 per 1000 (1 in 68) children.

The triad of symptoms comprising of impairments in socialization, communication and imagination are a result of multiple level abnormalities. This means that autism is a complex disorder with the root cause attributable to a mix of genetic, environmental and neural causes. There are many theories that researchers and doctors have put forth according to which anything that can produce structural or functional damage to the central nervous system (brain) can also produce the condition of autism.

a) Genetics

Explaining occurrence of autism, purely on the basis of genetics is a very complex task. How different genes interact with each other, how deeply are they responsible for a certain feature or characteristics, what defect is there in the gene, environmental triggers, and many other factors finally decides, whether a child is or would be autistic or not.

There is a lot of research done in order to find what role heredity plays in autism. Parents with a child with autism have a very common query whether they can plan for a second child and what are the chances that he/she may have autism. Similar query applies to siblings, with one affected with autism. There are numerous studies done all over the world in order to find this answer. In families with one child with ASD, the risk of having a second child with the disorder is approximately 5 percent, or one in 20. This is greater than the risk for the general population. Identical twin studies show that if one twin is affected, there is up to a 90 percent chance the other twin will be affected. (NIH autism fact sheet).

Advanced age of father may also be associated with an increased risk of autism. According to a study conducted by Dr. Dolores Maldepsina, a psychiatrist at NYU Langone Medical Center, "Diseases which are present without a family history, the origin is in the sperm of the man and that the risk goes up as the man ages.". Studies suggest that fathers more than 50 years of age were 2.2 times more likely to have a child diagnosed with autism than a father less than 29 years of age.

b) Prenatal environment

Prenatal and perinatal risk factors could be one of the most important environmental triggers for autism. The risk of autism is associated with several prenatal risk factors, including advanced age in either of the parent, diabetes, bleeding, and use of psychiatric drugs in the mother during pregnancy. Autism has been linked to birth defect agents acting during the first eight weeks from conception (rare). The biological reasons for this are unknown: possible explanations include increased risk of pregnancy complications, increased risk of chromosomal abnormalities, spontaneous mutations, etc. There are strong evidences which demonstrate that insult at around 26 weeks of pregnancy correlates to development of autism in the child.

- ***Infectious processes***

Prenatal viral infection has been called the principal non-genetic cause of autism. Prenatal exposure to TORCH (Toxoplasmosis, Rubella, rubella cytomegalovirus and Herpes) increases the risk for autism.

- ***Environmental agents***

Teratogens are environmental agents that cause birth defects. These include exposure of the embryo to thalidomide, valproic acid, and misoprostol. These cases are rare. Questions have also been raised whether ethanol (grain alcohol) increases

autism risk, but evidence is insufficient to determine whether autism risk is actually elevated with alcohol. All known teratogens appear to act during the first eight weeks from conception, and though this does not exclude the possibility that autism can be initiated or affected later, there is strong evidence that autism arises very early in development.

- ***Other maternal conditions***

Diabetes in the mother during pregnancy, obesity and hypertension during pregnancy are associated risk factors though its contribution is still not clear. Thyroid deficiencies in the first 8-12 weeks have been postulated to produce changes of autism. Thyroxine deficiencies can be caused by inadequate iodine in the diet, improper absorption or possible environmental agents such as flavonoids in food, tobacco smoke, and most herbicides. However, this hypothesis has not been proven yet.

Prenatal stress consisting of exposure to life events or environmental factors that distress an expectant mother, have been hypothesized to contribute to autism, possibly as part of a gene-environment interaction. This has been reported with retrospective studies that examined stressors such as job loss and family discord, and with natural experiments involving prenatal exposure to storms.

Prenatal high testosterone levels in the amniotic fluid (fluid surrounding the baby in the womb) and prenatal exposure to ultrasound waves have been fleetingly associated with autism, though no substantial evidence to support it has come through.

- c) **Perinatal environment**

According to a review done in 2007 to find the risk factors, autism is associated with some perinatal and obstetric conditions like low birth weight, gestation duration, and lack of oxygen to the child during childbirth.

- d) **Postnatal environment**

A wide variety of postnatal contributors to autism have been proposed, including gastrointestinal or immune system abnormalities, allergies, and exposure of children to drugs, vaccines, infection, certain foods, or heavy metals. The evidence for these risk factors is anecdotal and has not been confirmed by reliable studies. The subject remains controversial and extensive further searches for environmental factors are underway.

- ***Mercury***

Mercury poisoning has been thought to be one of the causes of autism. This cause has not been very well validated, since the features of mercury poisoning and autism do not match and evidences so far are indirect. The sources of mercury are fish, inorganic substances, cosmetics and vaccines. A meta-analysis published in 2007 concluded that there was no link between mercury and autism.

- ***Thiomersal***

Perhaps the best-known hypothesis involving mercury and autism involves the use of the mercury-based compound thiomersal, a preservative that has been phased out from most childhood vaccinations in developed countries such as the USA. Parents may first become aware of autistic symptoms in their child around the time of a routine vaccination. There is no scientific evidence for a causal connection between thiomersal and autism, but parental concern about the thiomersal controversy has led to decreasing rates of childhood immunizations and increasing likelihood of disease outbreaks. Because of public concerns, thiomersal content was completely removed or dramatically reduced from childhood vaccines in the 1990s. Despite this, the rate of autism continued to climb in the late 2000s. A causal link between thimerosal and autism has been rejected by international scientific and medical professional bodies.

- ***Lead***

Lead poisoning has been suggested as a possible risk factor for autism, because the lead blood levels of autistic children have been reported to be significantly higher than typical. The atypical eating behaviors of autistic children, along with habitual mouthing and pica, make it hard to determine whether increased lead levels are a cause or a consequence of autism.

- ***Lack of vitamin D***

There is some very limited support based on available research for the hypothesis that vitamin D deficiency as having a role in leading to autism. More research is required to substantiate this.

- ***Viral infection***

Many studies have presented evidence for and against association of autism with viral infection after birth. Though various viral infections, such as herpes virus infection, have been thought to trigger autism like features but showing a direct role for viral causation is difficult in those diseases, and mechanisms whereby viral infections could lead to autism are speculative.

- ***Vaccines***

The scientific consensus is that there is no evidence of a causal relationship between vaccinations and autism. Despite this, many parents believe that vaccinations cause autism and therefore delay or avoid immunizing their children under the "vaccine overload". Hypothesis. They believe that giving many vaccines at once may overwhelm a child's immune system and lead to autism. This hypothesis has no scientific evidence and is biologically implausible. A study published in the Journal of Pediatrics on April 2013 found no correlation between autism and the antigen number in the vaccines which were administered to the children up to the age of two. This study disproves the 'vaccine overload' theory.

- ***MMR vaccine***

The MMR vaccine theory of autism is one of the most extensively debated theories regarding the origins of autism. Andrew Wakefield et al. reported a study of 12 children who had autism and bowel symptoms, in some cases reportedly with onset after MMR in 1998. This paper was later retracted after 12 years as the researchers did not prove an association between measles, mumps, and rubella vaccine and the syndrome described. Numerous peer-reviewed studies since, have also failed to show any association between MMR vaccine and autism.

The Centers for Disease Control and Prevention, the Institute of Medicine of the National Academy of Sciences, and the U.K. National Health Service have all concluded that there is no evidence of a link between the MMR vaccine and autism. The risks of disability or death of a child due to a disease like measles is much higher than any minor risks due to vaccination.

- ***Autoimmune disease***

Interactions between the immune system and the nervous system begin early during embryogenesis, and successful neurodevelopment depends on a balanced immune response. It is assumed that auto-antibodies that target the brain or elements of brain metabolism may cause or exacerbate autism, due to an environmental trigger after birth, viral infection etc. via autoimmune mechanism. A small percentage of autism cases are associated with infection, usually before birth.

- ***Oxidative stress***

Toxicity and oxidative stress are assumed to be a cause for autism in some cases. The evidence suggests reduction in the antioxidant capacity, increased markers for oxidative stress, and abnormal metabolic function. This is still not considered as a specific cause of autism because oxidative stress is also associated with many other conditions.

- ***Neurons or cells in the Amygdala***

Amygdala is a part of the brain, which is involved with social knowledge and cognition along with emotional responses. As children with autism exhibit problems with the "social brain" and emotional responses, damage of the cells in the amygdala is strongly implicated.

- ***Leaky gut syndrome***

Parents have reported gastrointestinal (GI) disturbances in autistic children, and several studies have investigated possible associations between autism and the gut. There is no research evidence that autistic children are more likely to have GI symptoms than typical children. A 2008 study found that children with autism had no more peptides in their urine than typical children, casting doubt on the proposed mechanism underlying the leaky-gut theory. In another example, a 1998

study of three children with ASD treated with secretin infusion reported improved GI function and dramatic improvement in behavior, which suggested an association between GI and brain function in autistic children, although the low number of patients is statistically insignificant. However, later studies found secretin ineffective in treating autism.

Also, many antibodies detections tests to detect possible allergens are being conducted to find out causes of a "leaky gut syndrome". However, these tests are inconclusive and form a poor base for any type of understanding of their relationship with autism.

- ***Opiate theory***

Opiate Theory hypothesizes that autism is caused by a digestive disorder present from birth which causes gluten (present in wheat-derived foods) and casein (present in dairy products) to be converted to the opioid peptides gliadorphin and gluteomorphin and casomorphin. According to the theory, exposure to these opiate compounds in young children interferes with normal neurological development by dulling sensory input. Lacking sufficient sensory input, the developing brain attempts to artificially generate the auditory, vestibular, visual, and tactile input on its own. This attempt at generating input manifests itself as behaviors common to autism, such as grunting or screaming (auditory), spinning or rocking back and forth (vestibular), preoccupation with spinning objects or waving of the fingers in front of the eyes (visual), and hand flapping or self-injury (tactile). The theory further states that removing opiate precursors from a child's diet may allow time for these behaviors to cease, and neurological development in very young children to resume normally. The scientific evidence is not yet adequate to make treatment recommendations regarding diets, such as the Gluten free Casein free diet, which excludes these substances.

- ***Refrigerator mother***

Early childhood trauma and withholding of parenteral affection has been linked to autism. But treatments based on these theories failed to help children with autism.

It's likely that in your child we may never find out definitely what caused him or her to have autism. Even if we did, then it's likely that we can do anything about it now. Whereas, we understand that, as a parent it's important for you to know why your child has autism. It's also important that we shift our focus to what's the best that we can do for the child in the future.

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3. Early Indicators of Autism

There are certain early signs of Autism, which can be picked up by parents. Many a times, the parents fail to understand the reason for unusual behaviors, inability to follow commands, which may lead to venting out stress and frustration on the child. Picking up early signs in your children may help you to intervene in early stages, thus yielding better outcomes. Early therapeutic management of the child may prevent complications.

What are the possible early indicators of Autism?

Enumerated below are some of the observable features of autism. Through your daily interaction with your kids, you as a parent or teacher could identify the early signs in different age groups.

Newborn to 18 months

- May avoid people's gaze
- Does not like people cuddling
- Prefers to be alone
- Delayed smile or does not smile
- Repetitive behavior or actions with the body, like hand flapping or rocking
- Repetitive behavior or actions with the objects, like with toys
- Avoids social interaction
- Has hyperactivity (excessive physical activity, restless, not sitting at one place) when there is a change in the routines
- Lack of non-verbal communication like gestures, poor facial expression and no body language

1½ years to 4 years

- May have impaired imitation (copying others' actions)
- May avoid people's gaze (not looking into person's eyes while interacting)

- Poor language comprehension (understanding the meaning)
- Not approaching parents for comfort, even when ill, hurt or tired
- Lacking awareness of other people's existence
- Older child may exhibit a failure to greet people or take turns while playing or interacting
- May have delayed language development
- Lack appropriate gestures
- Repetition of whatever is said to him /her (echolalia)
- Unusual manner of talking, e.g. squeaky, or sing-song voice
- Handles objects strangely, e.g. spinning or turning them or arranging them in a line
- Have unusual body movements, e.g. hand-flicking or hand twisting, spinning, head banging or whole body movements
- Preoccupied with parts of objects, e.g. playing with only wheels of a toy car. May have attachment to unusual objects, e.g. wires, threads, buttons, etc.
- Unreasonable insistence on following routines to precise detail
- Have difficulty in toilet training
- Have extreme fears

4 years and older

- Poor Eye contact
- Lack an awareness of the existence or feelings of others
- Absence of pretend play, e.g. dressing up a doll, or pretending to be a teacher
- Increased hyperactivity
- Lack or have unusual emotional responses, e.g. crying or laughing without any reason
- Indifferent towards or responds negatively to physical affection like hugging, patting, etc.
- Poor social interaction
- Not understanding conventions of social interaction, such as turn-taking, making requests, etc.
- Show little expressive language
- Delayed language development

- Inappropriate gestures, e.g. hugging strangers
- Fail to initiate or sustain conversations
- Meaningless speech
- Preoccupied with one or only a few narrow interests
- Insistence on sameness
- Attachment to unusual objects
- Spinning objects
- Show marked distress over changes in trivial aspects of the environment, e.g. position of a bag in the room
- Show unreasonable insistence on following routines in a particular and rigid way

The above age-wise list of symptoms will help you detect the early signs of autism so you can reach the experts at the earliest. Meanwhile, it must be noted that too much speculation can lead to unnecessary worries.

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4. Signs And Symptoms

What are the Signs and Symptoms of Autism?

1. Social relationship and reciprocity

The social issues (problems in interacting, forming and maintaining relationships) that children with autism face lead to serious problems in their everyday lives. Healthy infants show their interest in the world and people around them. For example, by his first birthday a toddler interacts with others by looking at people in the eye, copying words or actions of others, using simple gestures like clapping or waving, etc. But toddlers with autism have delayed milestones and they have a difficult time learning to interact with others and their environment. As these children grow up, they show a lack of interest in interacting with other people, which in turn leads to social isolation and other children not wanting to play with them.

People with autism have difficulty in communicating and expressing their feelings and trouble understanding the feelings of others. Eventually, as they grow up they may experience anxiety and depression which would make it difficult for them to adjust or adapt to social problems.

Examples of Social Issues related to Autism:

- Poor eye contact
- Does not respond to his name
- Prefers to stay alone
- Shows inappropriate expressions
- Does not understand non-verbal cues of others
- Has difficulty in understanding or expressing his/her own feelings
- Has difficulty understanding personal space and boundaries



Figure 4.1: Prefers to stay alone

2. Emotional responsiveness

- Unusual mood or emotional reactions - difficulty in recognition of facial expressions and the emotions behind them, imitate or use emotional expressions. They fail to understand and control their own emotions. Also due to lack of understanding and interpreting emotions of others they may seem to lack empathy.
- Fear of irrelevant objects or situations, for example fear of pressure cooker or a black plastic bag

3. Speech language and communication

Each child with autism spectrum disorder differs in communication skills from the others. Some of them can speak well, whereas others may be mute, still some others would have speech in the form of one or two words. About 25 to 30% of children with autism speak a few words at 12 to 18 months of age after which, they may be lost. Most of these children have a history of language developmental delay.

People with autism have a hard time using and understanding gestures, body language or the volume and tone of their voice. For example, an individual with autism may laugh while saying something sad.

Examples of Communication Difficulties are:

- Delayed development of speech and language skills
- Repetitive words or sentences over and over again (echolalia)
- Irrelevant speech i.e. gives unrelated answers to questions
- Does not point or respond to pointing
- Pretend play is absent, for example cannot pretend to feed a doll
- Does not understand jokes, riddles or questions

4. Behavior patterns

Individuals with autism often have unusual interests and behaviors.

- Self - injurious behavior like head banging, biting oneself, etc
- Aggressive behavior towards others like biting, scratching, pulling others hair, throwing objects, etc
- Plays with toys in an unusual manner
- Obsession with irrelevant objects like bottle caps, wires, buttons, key rings, water pipes, etc.
- Lines up objects or toys
- Minor changes in the routine or environment can be very upsetting
- Repetitive behaviors like hand flapping, rocking, spinning objects
- Smelling objects or people



Figure 4.2: Poor Eye Contact



Figure 4.3: Irrelevant lining up of picture cards



Figure 4.4: Closing his ears



Figure 4.5 : Irrelevant lining up of picture cards



Figure 4.6: Throwing temper tantrums



Figure 4.7: Aggressive behaviour



Figure 4.8 : Self - Injurious behavior



Figure 4.9 : Flat Feet



Figure 4.10 : Winging of Scapula

- Strong avoidance of certain food items, tastes, textures of clothing, etc.
- Unusual fears or dislikes, e.g. cutting nails, flowers
- Self stimulatory behaviors like rocking, tapping hands / feet
- Increased hyperactivity - inability to sit in one place for a long time, unable to complete any task, running around at home and in the classroom which makes it difficult for the teachers and parents to teach the child.
- Impulsive behavior, for e.g. acting without thinking
- Throwing temper tantrums

5. Sensory aspects

- Abnormal reaction to sensory stimuli - child can be hyperresponsive or hyporesponsive to sensory stimulus. For example-
 - a) Touch: avoids touch or seeks more physical touch like simple shake hand, parental superficial touch, kissing, hugging, etc. Avoids/seeks certain textured clothing, food, etc.

- b) Vvestibular: seeks movements of different body parts of body as a whole, e.g. rocking, swinging, bouncing, jumping, etc. Or avoids movements, e.g. fear of climbing down the stairs, avoids travelling in a moving vehicle, avoids swings, roller coaster rides, merry-go-round, etc.
- c) Proprioceptive (sense of the relative position of parts of one's own body): hyporesponsive child will show behavior like jumping, running, teeth grinding, fidgeting, walking too hard, holding pencil too tight, shake his legs or constantly bang the back of his foot on the floor/chair while sitting in class, crack knuckles, bite his nails till they bleed, chew his fingers and inedible objects like pencil, gum, clothing collar, sleeves, enjoy tight clothes, etc. Hyperresponsive child will frequently trip and fall, bounce into objects and people, difficulty climbing, running, riding a bike, slumping at the desk, appear to be lethargic all the time, poor posture and balance, etc.
- d) Auditory Inputs:
 - Covers ears to the loud noise of pressure cooker whistle or fire crackers
 - Runs out of restroom as the toilet flushes
- e) Visual Inputs:
 - Stares at spinning objects
 - Spins their own bodies
 - Looks beyond the person's face or avoids eye contact
- f) Taste and Smell Inputs:

Taste:

- Licks or tastes play dough or toys
- Won't eat certain foods (i.e. texture or taste problems)

Smell:

- The child may smell everything that he touches
- Won't use the washroom at public places

Due to sensory issues the child may avoid typical play or struggle learning new tasks which may cause lack of self confidence and self esteem.

6. Cognitive component

Cognitive skills in children with autism are varying and diverse. Some may have high intelligence but yet fail to judge others' intentions. They have difficulty in integration of information from surrounding environment and thus have impaired perception.

Others may have low IQ, low grasping power, short attention span, poor memory, get easily distracted, etc.

Children with autism may have 'savant skills' (extraordinary skills not exhibited by most persons). The most common savant skills involve mathematical calculations (multiply large numbers in his or her head), artistic and musical abilities (play a piano concerto after hearing it once), and feats of memory (quickly memorize complex maps).

While social and behavioral issues are more obvious in these children, some characteristic physical features may also be noticed. These may also add to their difficulties in interacting with their environment

Some Physical features of Autism are:

- Abnormal tone of muscle (too tight or too loose muscles)
- Poor proximal muscle strength (i.e. of shoulders and hip muscles)
- Winging of the Scapula (prominent shoulder blades due to weak muscles)
- Flat Feet
- Poor eye-hand coordination - clumsiness while eating, writing, ball catching, etc
- Limb apraxia, (difficulty in performing planned movements of the arms or legs) - difficulty combing hair, brushing teeth, making paper art, sketching and drawing, etc.
- Problems with intentional movements (difficulty in performing self-initiated movements) - clumsiness while reaching out to any object, etc.
- Balance problems while walking, climbing stairs and slopes, etc
- Sometimes lordotic (excessive inward curvature of the spine or back bone) posture
- Clumsiness
- Unusual sweating
- Rashes, dermatitis, eczema and /or itching

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5. Associated Problems

What are the other associated problems seen in Autism?

Children with autism are shown to have other co-existing problems. It is very important to determine whether the problem is a feature directly associated with autism or whether it should be diagnosed as completely separate condition in the child. Sometimes these problems would require specific treatment measures. Some common documented problems are listed below. Your child may or may not have some or any of these associated conditions.

A) Mood Disorders

Mood disorders are illnesses characterized by inappropriate or uncontrolled mood changes. Many studies have indicated that persons with autism are at an increased risk of developing mood disorders, particularly depressive disorder. Mood disorders can occur at any stage of life (childhood, adolescence or adulthood), irrespective of the intellectual ability of the person. Also, people with autism spectrum disorder may face a number of negative life events such as bullying and poor social acceptance especially during adolescent years. Such experiences may increase the risk of developing depressive disorder.

B) Obsessive Compulsive Disorder (OCD)

It is often observed that adults or children with autism display obsessive compulsive behaviors, for e.g. lining or arranging objects in a particular way. Children with autism generally have repetitive, preservative thoughts that are intense in nature, much like children with purely OCD symptoms. The difference is that children purely with OCD do not like the experience of having repetitive thoughts and would do anything to get rid of the thoughts (such as washing one's hands 25 times). Patients with pure OCD have an insight about the problem, whereas children with autism with associated OCD do not. Children with Autism Spectrum diagnoses are not bothered by their repetitive behaviors and thoughts, and instead are usually comforted by them (such as playing with a train in a repetitive fashion for hours at a time). However, there would always be a question

as to whether an additional diagnosis of OCD should be made in these children.

C) Seizures

Tuchman (2006) estimated that 25 % of autistic individuals also develop seizures which could be seen either in childhood (before 5 years of age) or during puberty (after 10 years) which may be triggered due to hormonal changes in the body. Some studies suggest that epileptiform discharges on electroencephalography (EEG) without clinical seizures can cause behavioral and cognitive impairment. All types of seizures can be associated with autism, which includes absence seizures (characterized by a brief loss and return of consciousness, generally not followed by a period of lethargy), tonic clonic seizures (loss of consciousness with tensing of muscles of the body, up rolling of eyes). Usually these seizures could range from milder forms, where the person would be gazing into space for a few seconds to a severe episode of seizure featuring large jerky movements of the whole body for several minutes.

It is usually seen that many of the autistic children have milder episodes of seizures that are difficult to notice, but may affect their mental functioning. Usually doctors prescribe drugs to control the seizure activity or frequency. It is very important that the child undergoes regular health checkups as these drugs could have side effects.

D) Sleep Problems

Many autistic individuals have sleep problems. The biggest sleep problems among these children include difficulty in falling asleep, inconsistent sleep routines, restlessness or poor sleep quality, waking early and waking frequently. These problems affect the overall health of the child and are associated with the child's aggression, depression, hyperactivity, increased behavioral problems, irritability and poor learning and cognitive performance. You as parents may also be exhausted due to sleep deprivation.

E) Learning Difficulties

Autism exists with any level of intelligence, but many individuals with autism also suffer from learning disability. Children with autism learn differently and often they are diagnosed as having learning disability such as dyslexia. Due to the abnormal networking of the brain, the learning process of children with autism is distorted. Normally, children learn new tasks in a similar way, but in children with autism, their learning process is extreme- either they learn a particular activity excessively and master it, or sometimes are unable to learn the basics of a simple task. A few others may have unusual abilities such as hyperlexia i.e. the ability to read at very young age. Some have exceptional mathematical abilities and fall under the "savants" category, while others have a tough time gaining mathematical skills.

F) Pica

Pica is characterized by an appetite for non-food and non-nutritive items such as chalk, paper, sand, paint, dirt, etc. It is seen that usually 30 % of children with autism have moderate to severe pica. Although consumption of some items may be harmless, pica is considered to be a serious eating disorder that can sometimes result in serious health problems such as lead poisoning and iron-deficiency anemia.

"I happened to leave my daughter Baby. Sunattended one afternoon and when I got back I was shocked to see my daughter eating a light bulb. She had almost wholly devoured the glass object. Then I rushed to a nearby doctor who evaluated her and said that she was all fine. I was surprised to know that in spite of consuming glass she didn't suffer from any damage. This was only one out of several such episodes. I have found her eating soap bars, shampoo, moisturizing creams, toothpaste, paint, clay, crayon, disinfectant, etc. What was surprising was how she never suffered any complications".

**G) Low Muscle Tone**

Children with autism usually have low muscle tone which affects their gross and fine motor skills. Low muscle tone is often described as "floppiness" i.e. the muscles appear to be less firm than usual. It is seen as a result of mild affection of the part of the brain which is responsible for maintaining the tone of the muscles (cerebellum). The child appears to be floppy and to have loose joints that show "hyper mobility" i.e. the ability to move limbs into awkward positions. The child may be less alert, have poor posture and attention. Also, the low tone affects their gross motor (crawling, jumping, hopping, etc.) and fine motor skills (writing, coloring, picking up small objects, buttoning, etc.).

H) Gastrointestinal Problems

Children with autism are more likely to have issues of the gastro-intestinal system affecting digestion and elimination. Data from a study by Loening-Baucke (1998) reported that 16-37% of children with autism have constipation. Lightdale et al. (2001), report that out of 500 patients 50% had frequent diarrhoea and 33% had abdominal pain. In children with autism, because of the leaky gut, they suffer from pain and discomfort. As they are unable to communicate the problem to the parents, it manifests as abnormal behavioral patterns. By treating gastrointestinal problems, we can help these children become more receptive to school, therapy, and social interaction. An endoscopy may be the only way to check for this problem. Consultation with a paediatric gastroenterologist is required.

With the above problems superimposed over the primary symptoms of autism, your child's ability to interact socially, behave acceptably, learn, communicate or play actively maybe further affected. They must be monitored and treated appropriately by the concerned medical professionals.

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SUMMARY :

Autism is now being recognized as a major medical condition with far reaching social implications. The increasing incidence of autism is a major cause of concern. However, with more clearly defined criteria for diagnosis and an increasing focus of the medical research community on the causes and possible treatments, children with autism now have a better opportunity to improve the quality of their lives.

It is however important that as parents, you are aware and alert in order to detect possible problems for appropriate intervention to be initiated as early as possible. On the other hand, over speculation and "self diagnosis" should be avoided. Always remember that the actual diagnosis is a combination of the observed symptoms, assessment by professionals and investigative procedures. While there are a variety of signs and symptoms that may be difficult to manage, the associated co-morbidities and problems can be controlled and are definitely treatable.



SECTION B

Diagnosis

6. Diagnosis And Assessment

Autism is one of those common conditions which remain unidentified or undiagnosed until very late into the developmental or formative years of a child. The reasons behind this are limited awareness of parents as well as denial or hesitancy in accepting their child's problems. This in turn, delays early intervention. Hence, this section outlines the path leading to early and accurate diagnosis of ASDs, the co-morbid problems and an understanding about the real problems.

How is Autism diagnosed?

As parents you would probably be the first ones to notice your child displaying some delay in development or unusual behaviors like failing to make eye contact, absence of a social smile or lack of response to his or her name. Those with the experience of parenting, may very well be able to identify the latter's developmental delays or socio-behavioral problems. First - time parents may however realize it much later. After these initial signs parents very often consult the child's pediatrician or their family doctor.

1. The very first sign is that the baby does not respond to any signals or gestures made by the parents thereby giving an impression that he/she might be deaf. Brain stem evoked response audiometry (BERA) is one of the first tests recommended by the family doctors or pediatricians to rule out hearing problems. This test however may not indicate any hearing defect as it is most case of children with autism.
2. Doctors may also prescribe an MRI or CT scan of the brain to examine the brain structure. Several other investigative tests could be suggested to rule out brain tumors or other defects. These scans are normal in most case of children with autism.
3. After which your family doctor or pediatrician may also request for few blood and urine tests to analyze the child's DNA for the presence of a Fragile X syndrome. Fragile X syndrome is a genetic condition involving changes/defect in the coding on a part of the 'X' chromosome. It is the most common cause for inherited intellectual disability (mental retardation) in boys.

Diagnosing autism in children becomes difficult as they do not display any obvious physical problems. Some children are then referred to a pediatric neurologist, child psychiatrist or a developmental pediatrician who may be able to assess the delays in the child's development across various milestones. This helps narrow down to the diagnosis of an Autism Spectrum Disorder.

The assessment of children with autism requires multiple evaluators, using multiple methods of gathering information. A formal diagnosis is best done by a team of professionals comprising of a developmental pediatrician, a child psychiatrist, a psychologist, an occupational therapist, a speech and language pathologist and a few others. This team carries out several assessments and tests, which pinpoints the exact areas in which the child has a problem. For example, social quotient/social interaction, comprehension/ understanding, hyperactivity, etc. All of these are described below in greater detail.

The Developmental Pediatrician

A developmental pediatrician would conduct a developmental screening which is a short test to evaluate the delays in the development that the child might have undergone. The pediatrician would:

- Ask parents about the milestones (step-wise developments like head holding, rolling, crawling, standing, sounds, babbling, speech etc.) of the child.
- Ask about the habits, abilities and the challenges that the child is facing.
- Play or talk to the child to see how the child speaks, behaves, learns, performs and moves.
- Conduct a thorough evaluation of the child's height, weight, coordination, responsiveness, etc.
- Advise an auditory testing for your child i.e. BERA, to rule out hearing problem.

The developmental pediatrician would identify problems based on the above interviews, observations and assessments. The pediatrician would specifically evaluate for ASD if your child has a history of preterm birth (delivery before completion of nine months of pregnancy), low birth weight or has a sibling with autism. Following detailed evaluation you would be provided with a detailed report along with treatment recommendations. You may be referred to a clinical psychologist, child psychiatrist, occupational therapist or speech therapist based on the child's presentations and diagnosis as per ICD- 10 or DSM- V criteria.

The Clinical Psychologist

A psychologist would first take a detailed history of the child i.e. his/her cognitive development (thinking, understanding, attention and concentration abilities), behavior, social functioning (interaction with other children, family members, responses to situations etc.), family history (identifying the presence of similar or related problems

in other members in the family), etc., after which various psychological tests specifically designed for autistic children would be conducted to evaluate their problems and to confirm the diagnosis.

The psychologist would conduct the following tests to confirm the diagnosis and to get an idea about your child's level of functioning at school, home and in social settings. A detailed report from the psychologist would help determine the appropriate treatment plan for the child. For example, depending on the Intelligence Quotient (IQ) test report and scores, the child may be placed in a special school, open school or a normal school as appropriate. The above mentioned tests would help in identifying the severity of autism (mild, moderate or severe) in your child. The psychologist also gathers brief information about your and immediate family members' attitudes, personalities, behaviors and coping strategies.



Figure 6.1 : Taking detailed Case History



Figure 6.2 : IQ test conduction

	Tests	What does it evaluate?
1.	Childhood Autism Rating Scale (CARS)	Differentiates children with autism from other developmental disorders
2.	Social Communication (SCQ)	Communication skills and social functioning
3.	Modified Checklist for Autism (M- CHAT)	Social communication and behavior
4.	Malin's Intelligence Scale for Indian	Children (MISIC) IQ i.e. intellectual functioning of the child
5.	Autism Diagnostic Observation Schedule (ADOS)	Social and communication behaviors related to the diagnosis of Autism

The Occupational Therapist

A comprehensive assessment is conducted by an occupational therapist which provides a detailed understanding of the child's history and overall development. A holistic assessment would take 2-4 hours and may be done in several sittings with breaks. The assessment lays the groundwork for individual goal setting and occupational therapy

treatment. Information about the child's abilities, deficits, needs and barriers are identified through interviews, observations and performance of standardized test batteries or proformas.

Standardized Assessment Instruments		Domains assessed
1.	Peabody Developmental Motor Scales (PDMS)	Gross Motor: Reflexes, Locomotor and Non-locomotor skills, Balance etc.
2.	Toddler Infant Motor Evaluation (TIME)	Fine Motor: Grasping, Eye-hand co-ordination, dexterity Mobility/ Stability, Functional performance, Social/Emotional abilities etc.
3.	Bruininks-Oseretsky Test of Motor Proficiency (BOTMP)	Gross and Fine Motor skills: Running, Balance, Strength, Co-ordination, Visual-Motor control, Speed and Dexterity
4.	Developmental Test of Visual Motor Integration (VMI)	Visual motor control for design copying and drawing
5.	Sensory Profile	Measures a child's sensory processing abilities and the effect on functional performance.
6.	Sensory Integration and Praxis Test (SIPT)	Measures visual, tactile, kinesthetic perceptions.
7.	Minnesota Handwriting Assessment	Rates the legibility, form, size, alignment etc.
8.	Test of Visual-Perceptual Skills (TVPS)	Memory, differentiation, sequencing, relations in space etc



Figure 6.3 - Occupational Therapy Evaluation



Figure 6.4 - Occupational Therapy Evaluation

Occupational therapists will assess child's abilities and difficulties in performing daily occupations/activities such as:

- Play
- School performance
- Gross motor skills (jumping, hopping, climbing stairs etc.)
- Fine motor skills (buttoning, lacing, using a scissor etc.)
- Sensory processing (understanding and using information from all senses)
- Hand writing
- Activities of Daily Living or ADL (eating, bathing, toileting etc.)
- Motor-perceptual planning, praxis (planning body movements and actions for a task)
- Behavior
- Communication and interaction skills
- Clinical observation including muscle tone, strength, bilateral integration and midline crossing, dominance, body awareness, postural control, and motor planning.

The assessment is summarized by the occupational therapist in a written report, which is used as a baseline for the intervention process. A comprehensive report explains clinical findings with respect to sensory/motor processing and integration, behavior and skills (self-care, play and schooling) and offers recommendations and practical strategies for the home and school environment.

The Speech and Language Pathologist

A speech and language therapist is one of the professionals involved in the multidisciplinary assessment of ASD. The therapist's role is to build up a profile of the child's communication skills, identifying strengths and weaknesses, in order to decide whether these may be associated with autism or whether they may be part of a different kind of problem. The therapist will build up this profile in a variety of ways which may include:

- Taking a developmental history
- Observing the child at home/play-school/nursery/school/clinic
- Assessing the child at home/play-school/nursery/school/clinic

The therapist will aim to observe and/or assess some or all of the following areas:

- Receptive Language which includes receptive vocabulary, concept understanding, grammatical understanding, verbal reasoning, expressive language including:

expressive vocabulary, sentence formation and narrative skills, turn taking, presence of echolalia or jargon (non-meaningful) speech and repetitive verbal behavior.

- Pragmatics which includes verbal conversation skills, understanding of jokes/ idioms, non-verbal communication like gestures or verbal tone etc.
- Play including functional play, symbolic and pretend play, social play, etc.
- Attention-concentration, listening skills, observation skills, thinking and reasoning.
- Checking oro-motor skills like tongue movements, lip movements, sucking, swallowing, chewing, blowing, oral hypo/ hyper-sensitivity like excessive or reduced gag reflex, persistence for particular textures of food, etc.
- Voice quality including use of intonation.
- Social interaction with peers, strangers, etc.
- Reading and writing skills.

The child's age and ability will determine if and how these aspects are assessed. Some of these aspects will also be observed/ assessed by other professionals, e.g. psychologist or occupational therapist.

Standardized Assessment	Usefulness
1. Normative chart developed by National Institute on Deafness and Other Communication Disorders, National Institutes of Health, U.S, Department of Health and Human Services	Gives an in depth information of how your child's speech and language skills develop
2. Communication and Symbolic Behavior Scales Developmental Profile	Can help identify babies at risk to develop autism symptoms in infants and toddlers between 18 to 24 months

The Physiotherapist

Although not all children with ASD are referred to physiotherapists, recent research has shown that physiotherapists have an important role to play in the overall management of some cases. A physiotherapist will do a comprehensive screening of your child to assess any physical issues. They may need multiple sessions to observe the child in various environmental settings, in order to identify the physical problems which the child may be facing, like at school, during play, while performing complex tasks. The physiotherapist closely assesses the system which is responsible for all the normal physical functions of the child - neuromotor and musculoskeletal systems. The aim of the physiotherapist is to assess:



Figure 6.4 - Occupational Therapy Evaluation

- How the child manipulates his body to different situations, tasks and challenges given to them?
- How the child manages the more difficult age appropriate motor tasks and what are the strategies which the child utilizes?
- How is the posture, attitude of limbs and trunk, faulty compensatory mechanisms which the child attains?
- What are the child's strengths and limitations that can be helpful in knowing the child and using them during their therapy to avoid unwanted disturbances?

An assessment by a team of professionals consisting of developmental pediatrician, clinical psychologist, occupational therapist, physiotherapist and speech and language pathologist is viewed as an ongoing team effort. For example, a team of professionals work together, to provide a comprehensive assessment of a child's development. After which they then continue to work with families to make recommendations for educational services, medical care and other critical services for children on the spectrum. This multidisciplinary approach is extremely valuable as it helps in creating a comprehensive treatment plan which allows in coordinating an intervention plan for the child which will help improve the condition of the child.

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7. Investigations

What are the investigations conducted for Autism?

There is no one diagnostic test for autism. Usually autism will be suspected based on clinical picture. Prior to diagnosis based on clinical observations and standardized assessment tools, you may be requested to perform one or more of the following investigative procedures for your child. These will help in ruling out other disorders and confirm the diagnosis of autism.

A) Neuro-imaging studies (MRI/CT/PET-CT/SPECT/FMRI)

Neuro-imaging procedures are painless, non-surgical methods which provide a view of the brain structure and function in two or three-dimensions. Computerized Tomography (CT) and Magnetic Resonance Imaging (MRI) of the brain reveal gross structure in different views as well as any gross defects. Predominantly they reveal the anatomical pictures of the brain such as size, shape, structure, location, etc. However, most children with autism have a near - normal MRI and CT scan of the brain.

In recent times, however a new investigative modality called functional neuroimaging is being explored to identify functional problems in the various brain areas.

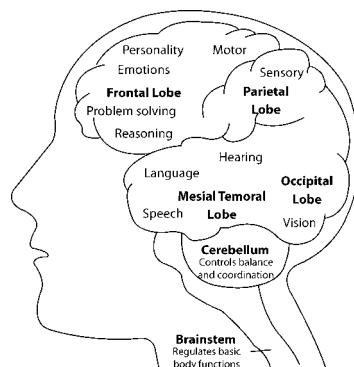


Fig 7.1 Areas of the brain

Functional brain imaging, such as positron emission tomography (PET), single photon emission computed tomography (SPECT) and functional MRI (fMRI) have added a new perspective to the study of normal and pathological brain functions. PET-CT scan measures the metabolism of the brain, SPECT measures the blood flow to the brain and fMRI measures the activation of the brain during a particular task. These imaging studies have shown bilateral hypoperfusion of the temporal lobes in autistic children. In addition, activation studies, using perceptive and cognitive paradigms, have also shown an abnormal pattern of cortical activation in autistic patients. This suggests that different connections between particular cortical regions could exist in autism. Thus, in autism even though the MRI is normal, due to the functional abnormality the PET-CT/SPECT/fMRI will be abnormal.

What happens in autism and how brain Imaging helps understand Autism?

Though, autism is a very complex neurodevelopmental disorder, various different studies have also tried understanding the basic pathophysiology of autism or, in simple terms, why autism develops and what happens in the brain. Routine MRI Brain studies generally show normal structure hence, for a long time, it was not understood, what exactly is the problem in the brain.

In autism though the brain structurally looks normal, there are functional abnormalities in specific brain regions like mesial temporal lobe, frontal lobe and cerebellum. These areas are responsible for organizing sensory input, auditory perception, language and speech production, memory association and formation and emotional expression. These probably co-relate to the kind of issues seen in autism. The cerebellum is also important for balance and coordination.

The two major mechanisms of brain damage in autism have been postulated as

- a) decreased blood flow to specific brain regions like in the medial temporal lobe and perhaps, more specifically the amygdaloid complex. Distinct patterns of memory losses and socio emotional abnormalities emerge as a result of extent of damage to the medial temporal lobe structures. This has been supported by abnormal findings on special imaging techniques, such as PET CT, SPECT and fMRI Scan of the brain. Apart from bilateral decreased blood flow to the temporal lobes in autistic children, brain activation studies, using perceptive and cognitive paradigms, have also shown an abnormal pattern of cortical activation in autistic patients. This means that, there is reduced blood flow supply to certain specific areas of the brain, which in turn could be the cause of reduced functioning in this area. This coupled with an imbalance in the activity, overall in the brain, is possibly responsible for the manifestations associated with autism.

Further to this, Brain SPECT has established a relationship between regional cerebral flow and development quotient (intelligence quotient) in the left laterotemporal and both dorso-medio-lateral frontal areas, and cerebellar vermis area. This goes to show that cerebral blood flow decrease in the temporal, frontal

areas and cerebellum relates to the brain damage in autism as well as decreased intelligence levels.

- b) Immune imbalance in brain - Studies have shown that there is increased inflammation of the brain in autism. This inflammation will cause decreased functioning of neurons and thereby brain activity. The damage to the neurons will cause decreased metabolism of the affected brain areas which can be picked up on PET-CT scan. There is an imbalance in the overall brain metabolism. So, on PET-CT scan of brain some areas like cortical areas may show increased activity/metabolism and at the same time other areas like mesial temporal area and cerebellum may show decreased activity/metabolism.

PET-CT scan :

A PET - CT scan measures the brain glucose metabolism, reflecting functional activity of various areas of the brain. For a PET-CT Scan, a radioactive dye tagged to glucose is injected through the veins, which reaches the brain in about 30 minutes. During this time, the child is kept in a dark room. Following this, the brain is imaged and we can view the brain activity levels or metabolism depicted by a color scheme on the images.

In many cases of autism, the MRI of the brain may be near normal. Hence, studies are exploring the PET-CT scans in children with autism, in order to figure out which areas have anomalies and contribute to the deficits or problems. Some findings report problems related to the functioning of the temporal lobes of the brain, including the hippocampus and the amygdala.

Some representative PET CT Scan Brains, of children with autism, shows the areas affected in the below figures.

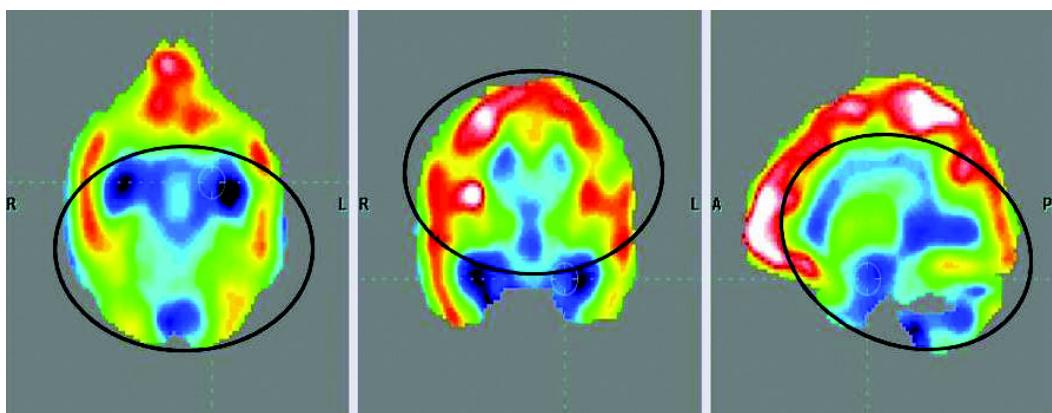


Figure 7.1 : Red areas depict hypermetabolic (hyperfunctioning) areas of the brain, while blue/black areas depict hypometabolic (hypofunctioning) brain areas.

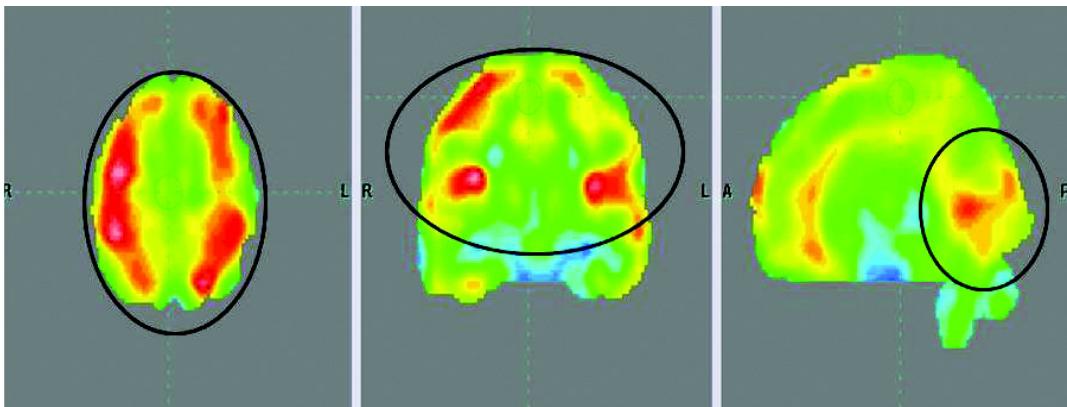


Figure 7.2 : Red areas depict hypermetabolic (hyperfunctioning) areas of the brain, while blue/black areas depict hypometabolic (hypofunctioning) brain areas.

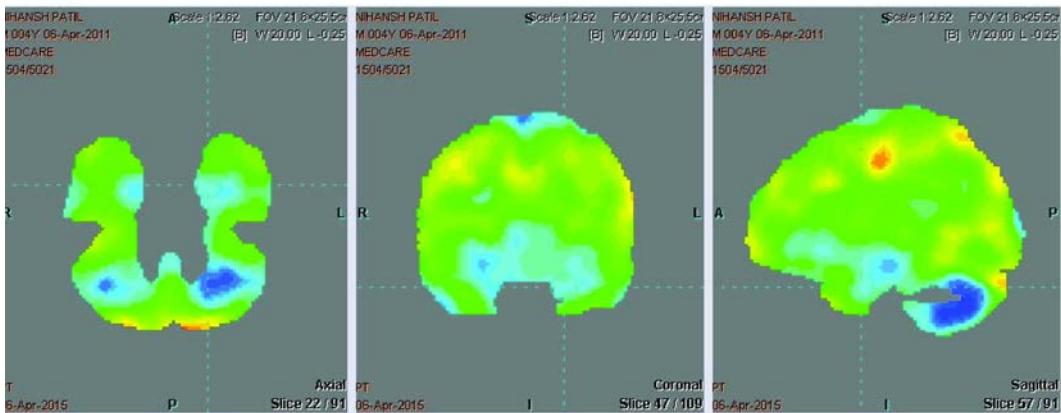


Figure 7.3 : Mild hypometabolism involving both mesial temporal cortex and right cerebellum. Moderate hypometabolism involving left cerebellum.

B) Electroencephalography (EEG)

An EEG is a test that records the electrical activity of the brain by the use of sensors across many different areas on the scalp. This was one of the earliest methods used to study the neurobiology in autism. For the EEG the child must be asleep at least for half an hour. If the child does not fall asleep automatically, medication may be given to induce drowsiness. While the child is lying down on a bed, about 20 electrodes are attached to his or her scalp from which the brain wave patterns are recorded.

Spence and Schneider (2010) in their review have reported the prevalence of epilepsy in autism. The estimate varies between a minimum of 5% to a maximum of 46%. It has been determined that there are 33 specific patterns on the EEG that differentiate an autistic child from a neurologically typical child. In some cases of

autism associated with a high frequency of epileptiform seizures (convulsions), the EEG will be abnormal. Approximately 30% of ASD patients without clinical seizures are found to have epileptiform abnormalities.



Figure 7.4 : EEG

C) Brain Stem Evoked Response Audiometry (BERA)

Also called auditory Brain-Stem Response (ABR) or Brainstem Auditory Evoked Response (BAER), this is an objective method of picking up brain stem (part that connects brain and spine) potentials in response to audiological click sounds. These waves are recorded by electrodes placed over the scalp. Often in autism, there is delayed speech or failure to respond to name-call. It is then that your doctor may recommend a BERA test to rule out any hearing problems. In children with autism, usually BERA is seen normal; there is a problem in the processing of the sound/voices in the brain, and not with the hearing capability of the child.

D) Metabolic screening

Blood and urine lab tests measures how a person metabolizes food and its impact on growth and development. Some autism spectrum disorders can be treated with special diets as an adjunct.

E) Genetic testing

Since heredity is implicated as one of the causes of autism, genetic testing is performed. Genetic disorder like fragile X syndrome is known to occur with markedly increased frequency in autism. Recently, genetic investigations have

revealed additional abnormalities that occur more commonly in those with autism, but are not associated with a known syndrome.

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8. Early Detection During Pregnancy

Is it possible to identify autism during pregnancy?

Recent research by scientists at the Autism Research Centre at Cambridge University has identified ways by which a probable diagnosis of autism can be made prenatally (i.e. before the child's birth). There is a possibility of screening unborn babies to detect autism in the womb itself.

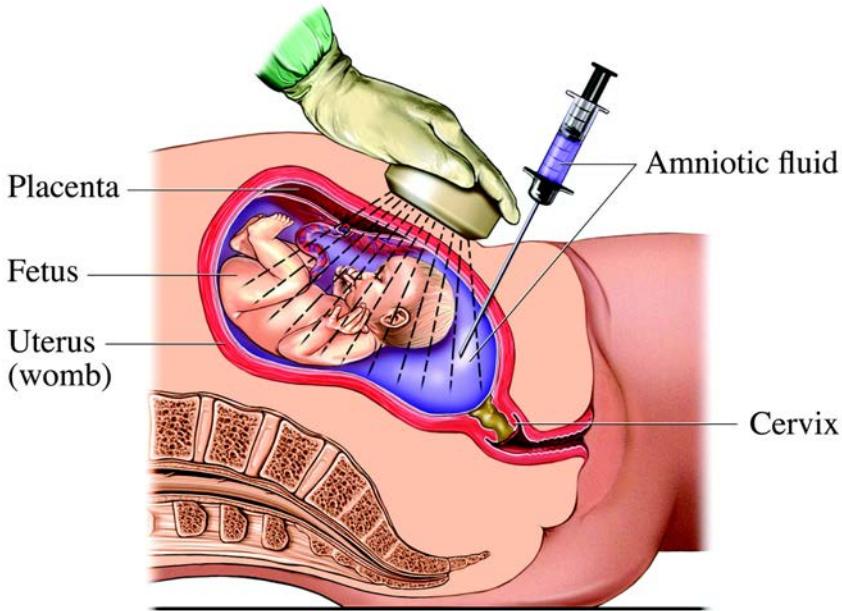


Figure 8.1: Amniocentesis

High levels of testosterone (a hormone) in the amniotic fluid of pregnant women are associated with autistic traits in children. This screening process is known as

amniocentesis. It is usually done between the 15th and 18th week of pregnancy and sometimes as early as week 11 of pregnancy. The test involves removal of a small amount of amniotic fluid that surrounds the fetus through a fine needle, under local anesthesia. This fluid is then sent for lab tests.

Chromosomal Microarray Analysis (CMA)

CMA is a novel method of analyzing chromosomes for detection of autism. With a single test, CMA can detect genetic abnormalities on all chromosomes simultaneously. It has much higher sensitivity than the older chromosome test called karyotyping. It uses the amniotic fluid as sample for testing and is taken with the procedure of amniocentesis as mentioned above.

These tests are secondary to clinical screening and may not be confirmatory, but definitely aid in medical decisions. The question arises when the parents are to make decisions based on the valued information they are provided with. Termination of pregnancy brings up several ethical, cultural and religious issues. Laws of the government and advice from a qualified doctor must be adhered to. We refrain ourselves from giving you any recommendations on this subject. Whether prenatal detection of ASDs is a boon or a bane is a highly debatable subject at this point.

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9. Reducing The Possible Risk Factors (For 'To-be Parents')

What are the risk factors associated with autism and how can you reduce them, if you are planning a child or are expecting parents?

As 'to-be' parents or for those who are planning a sibling to their child with autism, information about the possible risk factors and measures to reduce the risk of ASDs can be beneficial. Researchers have identified several factors that may be associated with autism. Monitoring these could lower the possibility of autism in your child.

Some of the known pre-natal (during pregnancy) factors

There are certain factors which can be modified and some which cannot. The modifiable ones should be taken into consideration and implemented to the best.

Modifiable: The following factors should be avoided

- Taking antidepressants, particularly in the first trimester (first three months of pregnancy)
- Nutritional deficiencies early in pregnancy especially folic acid deficiency
- Maternal infections
- Maternal stress
- Exposure to chemical pollutants such as metals and pesticides
- Exposure to harmful rays or extreme environmental conditions
- Exposure to some harmful drugs during pregnancy

Non-modifiable:

- Mother's autoimmune disorders such as celiac disease and rheumatoid arthritis.
- The age of the mother and the father- research studies have indicated that children

born to older fathers have a higher risk of suffering from autism.

- A parental history of schizophrenia-like psychosis, affective disorders including depression or bipolar disorder.

Measures you can implement to control pre-natal factors

- Taking a Multivitamin: As per the Centres for Disease Control and Prevention (USA), taking 400 micrograms of folic acid every day is very useful to prevent birth defects. Although not proven whether this will help reduce risk of autism or not, taking the vitamins will only be beneficial and not cause any harm to the unborn baby or the mother.
- Medications: Pregnant women taking drugs to handle depression during pregnancy must discuss the risks and benefits of these drugs with the concerned medical professional. This does not mean that pregnant women must avoid anti-depressants completely. Untreated depression in a mother can actually affect the well being of the child. Hence antidepressants must be taken after understanding its possible impact and carefully weighing the pros and cons of taking it.
- Expectant mothers should ensure that they eat nutritious food, avoid infections, and have regular medical check-ups.
- Observe appropriate ante-natal care as prescribed by your obstetrician, gynecologist or therapist.
- Expectant mothers should try and surround themselves with positivity and a stress-free physical and social environment.

Natal and Post- natal factors

Several Natal (during delivery) and Post-natal (after delivery) factors have also been identified to have a strong association with a diagnosis of autism. Only some of these cannot be controlled to a certain extent. A history of any of the following events during or after delivery must alert you as well as your doctors. Careful monitoring of the child during the developmental stages of life can give you an early diagnosis of ASD and access to appropriate intervention. The factors identified are:

- Breech presentation at birth i.e. buttocks first instead of head
- Low Apgar scores (Apgar scores evaluate a baby's well-being at 5 minutes after birth)
- Birth before 35 weeks of gestation.
- Low birth weight
- Lack of adequate blood flow to the brain during the birth process due to twisting of umbilical cord around child's neck, delayed cry after birth etc.
- Fetal respiratory distress (breathing difficulties)

- Birth injury or trauma,
- Newborn seizures
- Multiple births (twins, triplets, etc.)
- Anemia (low blood iron)
- Child being born in the summer
- Certain medical conditions such as tuberous sclerosis, congenital rubella syndrome, Fragile X syndrome, and untreated phenyl ketonuria

Measures you can implement to control natal and post-natal factors

To prevent some of the above events it must be assured that delivery is performed by a qualified professional only at a hospital. Conditions like rubella, tuberculosis and phenyl ketonuria must be treated appropriately and immediately. Certain risk factors for autism are not preventable. However, getting thorough prenatal, natal and post-natal care as appropriate can only benefit children in general, if not also helping to minimize risk factors for autism.

The Centers for Disease Control and Prevention (USA) has also identified that among identical twins, if one twin has autism, then the other is affected about 75% of the time. The figure for non-identical twins is about 3%. In families with one child who has an ASD, there is a 2 to 8 % chance of their second child also having an ASD. If you are a parent of a child with autism, these numbers will help you decide about or plan for another child. This information may be useful in preventing autism, but it carries with it its own set of moral and ethical issues. It is advisable to consult a genetic counselor for better guidance as you must make an informed decision regarding family planning.

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SUMMARY :

It is important that as parents you are aware and alert in order to detect possible problems for appropriate intervention to be initiated as early as possible. On the other hand, over speculation and "self diagnosis" should be avoided. Always remember that the actual diagnosis is a combination of the observed symptoms, assessment by professionals and investigative procedures. While there are a variety of signs and symptoms that may be difficult to manage, the associated co-morbidities and problems can be controlled and are definitely treatable.



SECTION C

Symptomatic Management

10. Social Relationships And Reciprocity

Understanding social relationships and reciprocating to them appropriately is one of the most important part of individuals life. In children with autism, it is largely affected, thus having major problems with social interaction and communication with people around them. You as parents play a critical role in improving your child with respect to these areas, as you spent most of your time with them, and understand their strengths and weaknesses very well. How can you improve each of the symptoms seen in your child is discussed below. There are certain activities mentioned, which you can perform with your child at home to help them improve in these domains. There are certain behavior modification strategies, which may be useful to help improve your child's social interaction and target all the problem areas mentioned below.

- **If your child has poor eye contact:**

When your child is unable to sustain his vision at a particular object or a person, it becomes extremely difficult to train the child for any purpose. This leads to inadequate attention span. Therefore, maintaining eye contact forms the basis for all types of learning and training.

- Visual (sight) and auditory (sound) stimuli can be used to improve eye contact. Move flickering lights in front of the child's eyes & demonstrate how he could track the light with his eyes. You can also make your child look at mobiles, lava lamps, bubble lamps, disco globes, colored rotating discs and colored light bulbs. Reinforce this behavior by giving the child things he likes in small quantity. Regular practice is necessary to increase the duration of eye contact. For example, ask the child to track a light/ sound stimulus (torch, bell, mobile phone etc.) from top to bottom or even from left to right side. Place an eatable or candy at the end point. If your child wants to eat, he must track the light/ sound stimulus from top to bottom.
- Hold some glittering object near your eyes and encourage child to look in your eyes. While being fed make it compulsory for your child to look into

- your (parent or caregivers) eyes. Avoid fluorescent bulbs (visual flicker, noise, and mercury content in compact fluorescents).
- Maintain a "Safe Space" at your home. It means maintaining a space which is free from distractions, with minimal visuals and objects, and keeping only those objects which you want your child to focus on.
 - If the child had a preference of any specific type of clothing, color, interior decorations, keep them in mind and respect them, as it will make your child more comfortable in his environment. Avoid complicated prints and patterns on clothing, walls, and floors
 - To avoid confusion and preventing visual overload, try to keep minimal amount of toys in the room at one point of time.
 - Other activities which you can integrate in his daily routine includes looking at photos, picture books, nature - fish tanks, farm, zoo, ocean, watching cartoons and movies
 - Activities like spot the differences, find the odd one out, follow the light, etc will also help in increasing his time of eye contact.
 - " Engages in solitary and repetitive play activities:
 - Problem of solitary or repetitive play in children with autism is a common feature. This can be reduced by improving the attention and concentration of your child to more productive and fun activities. Redirect your child to a different activity, object or play, which are more fulfilled and interesting for the child. Improve your child's attention and concentration with the activities which are mentioned in the section of Cognitive component.
- **Unable to take turns in social interaction/ Lacks social smile, remains aloof/ Unable to respond to social/environmental cues:**
 - Teaching your child to recognize feelings / facial expressions: Many children with Autism have a lot of trouble labeling and understanding the emotions of others'. This is a huge barrier. An amazing method to help your child label another's emotions is by using picture cards. Picture cards are cards, each with a face showing a different emotion. Ask your child to label the emotions on the cards, explaining to them what each facial expression is and what it means. For example, receiving a chocolate and a happy (smiling) face beside it. Similarly, not receiving a chocolate beside a sad face, breaking a vase beside an angry face etc.
 - Practice Social Interactions: Children with autism often have one-sided conversations. They may continue talking only about what interests them. Teach your child how to ask questions during a conversation, and how to wait for a response. Allow your child to ask you a question, answer it, and then request for another question
 - Use social stories: Social stories are simple stories written from a child's point of view. Each story describes situations which the child can learn from. The stories model what is expected of the child during each social situation.

For example, a child with autism may invade into someone's personal space by positioning themselves very close to the individual they are interacting with. This would make the speaker very uncomfortable. To avoid such instances, use vocal reminders or cues. Another strategy to solve this would be to tie a rope around the child's waist, leaving a 3 foot tail behind. Practice this with peers holding the tail and demonstrating to the child the meaning of 3 feet difference.

- Using role-play: Role-play (act out) social situations with your child. Demonstrate what to do in a social situation and then allow your child to do the same. List different social situations on flash cards, and then take turns. Acknowledge your child when he is doing a good job, and also explain what he could do better.
- Use videotapes or television to reinforce learning about facial expressions and sounds of emotions.
- **Does not maintain peer relationships/ Does not reach out to others/ Unable to relate to people:**
 - Providing as wide a range of communication and social opportunities as appropriate to your child as possible, such as playing in the garden or attending birthday parties.
 - Often children with autism have poor self-esteem and lack confidence. These may normally present as poor eye contact, difficulty in socializing or stammering while speaking etc. Facing a lot of rejection from peers, being talked about by concerned family members or teachers and being teased or bullied etc. contribute to their feelings of dejection and low esteem.
 - Keep a track of the child's behavioral achievements and encourage them by providing appropriate rewards in front of family members or peers.
 - Even if the child demonstrates poor or undesirable behaviors never take away his previously earned rewards.
 - Reward him/ her for minor positive changes in behavior.
 - Be specific about the behaviors that are liked and encourage them with a reward.
 - Behaviors that are undesirable need to be changed by desirable ones.
 - Phrases like "good boy" or "bad boy" should be avoided. Phrases such as "You followed the directions well", should be used to improve confidence levels.
 - The child's strengths should be highlighted and opportunities should be provided to encourage the use of his/her strengths. For example, a child who enjoys music should be encouraged to learn to play an instrument and motivated to excel at it.
 - When the child uses negative words, phrases or sentences referring to himself, encourage him to make changes in his/her dialogues to a more positive

description of himself/ herself.

- Encourage the client to maintain a scrap book comprising photos of his achievements or good behaviors. For example, if he/she won some competition or made a clay model, take a picture of it and display it in front of the child.
- The child's grades, health concerns and short comings should be kept confidential and not publicized or discussed openly (especially not in front of them).

Other therapies which have been found to effective adjuncts include art and play therapy and animal assisted therapy which are discussed in the respective sections. As animals do not like loud screaming or tantrums, they will often shy away from them. Therefore, if the child wants to spend time with the animal, he will begin to change his behavior. There are also certain medications, which have shown beneficial effects in certain studies on some children. There can be classified as prescription and non prescription medications. Prescription medications include selective serotonin reuptake inhibitors (SSRIs) like fluvoxamine, fluoxetine; dimethylglycine (DMG), venlafaxine which is an antidepressant; and acetylcholinesterase inhibitors like rivastigmine, donepezil, and galantamine. Non prescription medications include multivitamin/Mineral Supplements and Omega-3 It is best to consult your doctor to check if your child needs any medications and if they do which ones are best suitable. The detailed description of all the above activities is mentioned in the sections of psychological intervention and occupational therapy.

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11. Emotional Responsiveness

- **Shows inappropriate emotional response :**
 - Consistency is of the utmost importance. Whatever strategies you decide to use to help your child should be used by everyone involved with him, including other family members and professionals such as teachers. Inconsistent reactions to behavior by different people cause confusion; stress and frustration for someone with an ASD, and can make the behavior more difficult to tackle.
 - 'Time out' is a way for your child to calm down, especially if environmental factors, such as flickering lights, are causing distress. Whatever place your child goes to should be a calm, safe environment where they can be observed (May, 2005). This should only last a few minutes and your child then directed to an activity they find relaxing (May, 2005). Some children have time out at home, perhaps time alone in their bedroom, or the chance to do a favourite activity.
- **Shows exaggerated emotions / Excited or agitated for no apparent reason:** Persistence, practice, patience, and consistency are the ingredients to succeed in teaching your autistic child acceptable social behaviors. As the child grows and understands the norms he/she will be able to control and monitors his/her own behaviors. An internal locus of control will develop eventually that works best when the child needs to function by himself.
 - As previously mentioned, children with an ASD can have difficulties processing sensory information. Some things in their environment can act as severe irritants. If this is the case, it can be easier to remove the thing that might be irritating your child rather than trying to change a behaviour pattern. Are there flickering lights, humming noises or smells that may be causing distress? Remember that it may be something you have hardly noticed at all, while your child experiences it much more intensely.
 - As your child learns a new skill or coping strategy, give him or her as much praise as possible.

- Some children like verbal praise, others might prefer to get another kind of reward, like sticker on a star chart, or five minutes with their favourite activity or DVD. Try to give your child praise in a way that is meaningful.
- **Engages in self stimulating behavior:**
 - Presence of self stimulatory behaviors like hand flapping, rocking are seen in children with autism. One of the best ways to reduce these behaviors is redirection or replacement of the behavior. Redirect your child's attention to another activity or object, when you find your child showing any kind of self stimulatory activity.
 - For example, if spinning a wheel is a child's behavior of choice, a building gears toy may be an appropriate replacement, giving the child an opportunity to spin, but to do so in an appropriate manner. Other replacement behaviors may include substitute sensory providers: squeeze balls for the active hands, a ball between feet for squeezing ankles together for the active feet, hands in pockets while walking for the wandering and flying hands and fingers, etc. The challenge here is usually to find the appropriate replacement behavior.

- **Lacks fear of danger:**

This could be as a result of dysfunction of their systems which are responsible to maintaining body's position in space and balancing themselves (proprioceptive and vestibular system). Some common signs of proprioceptive dysfunction are clumsiness, a tendency to fall, a lack of awareness of body position in space may fall down a lot, They may also have trouble knowing where their body ends and objects begin (running a hand over a wall to determine body placement, infants may confuse mother's body as part of their own). The system could be either hypersensitive or hyposensitive. In hypersensitivity, have fearful reactions to ordinary movement activities (e.g., swings, slides, ramps, inclines). They may also have trouble learning to climb or descend stairs or hills; and they may be apprehensive of walking or crawling on uneven or unstable surfaces. As a result, they seem fearful in space. In hyposensitivity, the child may actively seek very intense sensory experiences such as excessive body whirling, jumping and/or spinning. This type of child demonstrates signs of a hypo-reactive vestibular system; i.e., they are trying continuously to stimulate their vestibular systems. This may lead to loss of balance if the head is tilted or trouble in recovering from movement (i.e. car sickness, dizziness after swinging). They may also not get dizzy at all and may crave excessive movement (rocking, swinging). Thus these children lack fear of any falls or potential dangers. There are certain activities with which you can sensitize your child's vestibular and proprioceptive systems.

- Ice skating/sledding/skiing/Bungee Jumper
- Play in sand box with damp, heavy sand
- Use cardboard boxes with blankets and pillows to make forts

- Rearrange bedroom furniture
- Ride a tricycle/bicycle
- Ride a scooter/skateboard
- Amusement park rides
- Swimming
- Push a grocery cart or stroller
- Brain Gym and yoga exercises
- Roll down a hill
- Use monkey bars, Climb stairs, climb an inclined ramp, Climb ladders
- Jump on mini-trampoline
- Use Sit n' Spin, Dizzy Disc Jr., or other spinning toys

There may be a time when your child experiences a meltdown. It is the sheer loss of control over one's behavior. It is exhaustive, frustrating, loud, scary and at times, risky. It is the ultimate cry for help. It means that the child needs your help to regain his composure. There are certain pointers which you can keep in mind when your child faces a meltdown:

- Stop the activity that is ongoing. Do not try to teach anything.
- Use more concrete, simple language during a more stressful situation.
- Assign one person to responsibly communicate with the child, one-on-one, every time the situation goes out of control. Too many people talking simultaneously could only aggravate the problem.
- Plan and rehearse ahead your means of handling the meltdown.
- Time-outs work effectively for you and the child.
- Let loose whenever possible to avoid or curb the meltdown. Be affirmative when absolutely necessary. For example, you may continue to insist on putting on the seat belt but not on putting the books back on the shelf.

There are other therapies which add as good adjunct therapies to alleviate problems of emotional responsiveness. These include music and art therapy. There are also certain medications which have shown to reduce emotional hyper-responsiveness in some children. These include prescription medications like antidepressants (TCAs) like Nortriptyline, Desipramine, Risperidone and aripiprazole. These medications need to be taken only after prior consultation with your doctor to see if your child needs any of these and which is best suited for them.

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12. Cognitive Component

Children with autism have academic problems especially if they fall into the category of mental retardation or if they have associated learning difficulties. Their poor attention and concentration, comprehension and concept formations lead to a lag in academics. Special schools are exclusively designed to cater to the special needs of children with autism. The curriculum, infrastructure, teaching methods and professionals are specifically chosen to suite the requirements and abilities of these children. These schools admit children who may fall somewhere on the moderate to severe categories of autism. Children with an IQ score of less than 80 are good candidates for these schools. Schools catering to such a population often have their own protocols and methods of functioning, which are compatible and friendly for children with autism.

Inconsistent attention and concentration :

Attention problems can lead to poor behavior and learning difficulties. It is often assumed that a child is non-compliant, when he fails to pay attention to directions or focus on the task at hand. Several factors contribute to their inattention. Some of the following strategies could help reduce these factors:

- The desk on which the child sits to study should be dark in color and very tidy. Remove clutter from his desk and surroundings. It is seen that dark colored desks aid in sustaining attention for a longer time.
- A separate room should be allotted for your child to sit and study. The room should have less furniture and should be painted in a soothing wall color. While the child is studying the windows should be shut. as most of these children love to stare outside the window.
- Avoid sensory inputs from the environment that could disturb him/her, example bright lights, a noisy wind chime, loud sounds, too many people around him etc. Arrange for tests and difficult assignments must be completed in quiet room devoid of any distractions.
- A few autistic children are bothered by visual distractions and bright lights. To avoid such lighting and place the child's desk near the window.

- The hierarchical (most to least) list of activities that interest your child should be kept in mind. While performing activities of low interest provide adequate breaks or intersperse them with activities of greater liking.
- While teaching the child it's very important to keep in mind that there should be minimum distractions in the environment. Whereas, the books or the objects used to teach a child should be very colorful and attractive for the child. For example: books with glitter or books that are musical, etc.

Some more strategies have been enlisted in the chapter of speech therapy and psychological intervention

- **Shows delay in responding:**
 - Creating a visual room can be beneficial. Put in different colored lights, mirrors, colorful rotating discs, radium stickers of planets or stars, disco globes etc. Use them in a variety of ways to improve attention, concentration eye contact, thus increasing the overall arousal level of the child.
 - Various strategies of behavior modification like Positive reinforcement, Prompting, Redirection can help you to get the desired response frequently from your child.
- **Has savant ability:**
 - Certain children with autism have specific skills which they acquire innately
 - Make use of these abilities and strengthen your child's self confidence.
 - For example, some children are good in mathematical calculations, playing certain musical instrument.
 - They should be encouraged and all their energy should be channelized in to the same.

What are the effective strategies for teaching and educating a child with autism?

Children with autism have academic problems especially if they fall into the category of mental retardation or if they have associated learning difficulties. Their poor attention and concentration, comprehension and concept formations lead to a lag in academics. As teachers or parents the following list of teaching tips can be useful for you while educating your child:

- Usually these children are visual thinkers (i.e. they think, understand and learn using visual images). Pictures/images usually form their first language and thoughts would be their second language.
- Children with autism have problems with remembering sequences; hence parents and teachers should avoid long strings of verbal instructions. If your child can read, you could write down the instructions on a piece of paper. It is seen that

some children who are unable to attend to and follow oral commands, respond better to written instructions or directions.

- Many children with autism are good at drawing, computers, art, music, etc. These talents should be highlighted, encouraged and eventually turned into a vocation.
- Children with autism usually get fixated on subjects/objects like trains, cars, utensils, bottles etc. The best way to deal with the fixation is to use them to motivate school work. If the child likes trains then this could be used to teach reading and math. Read a book about the trains and do math problems with trains. For example, calculate how many compartments are there in a train.
- Many children with autism have difficulty in writing and producing good, legible handwriting. Repeated practice may only frustrate your child. Make writing enjoyable and fun. Use paints, crayons, water, sand etc. to improve writing skills. Use of computers, magic pens and white boards can also be interesting.
- While some children with autism may learn to read using phonics (correlating sounds with letters or groups of letters), others may just memorize whole words. Children with echolalia would learn best with flashcards and picture books which are used so that whole words are associated with pictures. For example, if you are teaching a verb (action word), then you could hold up a card which says "jump" and you could jump too.
- There are a wide range of audio visual CD's which are available in the market which are useful to teach the child different topics like colours, fruits, body parts, daily activities, etc.
- Singing maybe a talent in a few children with autism. These may sing even better than they speak. Memorizing in the form of songs can be helpful. Those who are extremely sensitive to sound may receive information given to them in soft and low whispers.
- Some individuals with autism have difficulty in processing visual and auditory inputs simultaneously i.e. they are mono-channel (they cannot see and hear at the same time). They should not be asked to look and listen at the same time. Give them either a visual task or an auditory task as their immature nervous system cannot process simultaneous inputs.
- In older non-verbal children and adults, touch is often a reliable sense of input. Letter or number recognition can be taught by letting them feel plastic or wooden letter blocks. Use paints, crayons, water, sand etc. to improve letter recognition.
- Some nonverbal children and adults will find it easier to associate words with pictures if they see the printed word and a picture on a flashcard. The picture and the word must be on the same side of the card.
- With sequencing being a major difficulty, teach them in a step-by-step manner. For example, putting on shoes: with your own hands, guide your child to feel the

shape and parts of his/her own feet. The next step is feeling the inside and the outside of a slip-on shoe. To put the shoe on, guide the child's hands to the shoe. Using the hand-over-hand method, slide the shoe onto the child's foot. This enables the child to feel the entire task of putting on a shoe.

- Have a flexible outlook and approach. The main goal is to teach the child, so teach the child the way he learns it. For example, it is not necessary that the child should learn names of colours from a book. Use board games or different objects (red T-shirt, green leaves, blue bottle, etc.) to teach him names of colors.
- Modify the homework and class work assignments for the child, according to his or her functioning and the possible barriers which could restrict his development.
- If your child is comfortable with a certain special educator or a teacher ensure that he/she is with your child throughout the academic year. Changing teachers or educators would confuse and upset the child. Keeping the educator constant helps develop a rapport and increases the chances of improvement.
- Use different modalities to teach your child so that he understands and grasps better. Use audio (rhymes), visual modes (computer games), practical demonstrations, stories, rhymes, movies etc.
- Children with autism have poor eye hand coordination, poor understanding of problem solving and they take a long time to respond for which different activities like solving puzzles, mazes, and board games can be used to improve these functions.
- Practice is extremely important. For example, if you are teaching the child red colour then do not teach him any other colour till his concept of red colour is clear and at regular intervals ask him to differentiate between other colours.

Recently, Cognitive Behavior Therapy (CBT) has been adapted to address the needs of high functioning autism individuals and their families. CBT is based on the idea that how we feel, think, and behave are naturally intertwined. For this reason, CBT sets out to help patients identify the relationships between unhealthy thinking patterns, disruptive behavior, and negative emotional responses in upsetting or impairing situations. Consult your clinical psychologist for further details of this therapy approach. Other therapies which can be taken up as an adjunct to the above therapies include Music and Dance therapy. Certain medications can help in improving attention span in children with autism. These include multivitamin/mineral supplements, combination of Vitamin B6 and magnesium, stimulants such as methylphenidate, amphetamine, and dextroamphetamine which regulates the dopamine levels in the brain. It is important to consult your doctor before starting your child on any of these medications, to see which one suits the best for them. The detailed discussion of all the above activities is mentioned in the sections of psychological intervention.

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13. Speech, Language And Communication

Problems with speech and language are one of the major concerns for all the parents of children with autism. In desperation to make them talk and verbalize, the parents fail to connect with their children, thus building up on frustration in their relationship. Whether expression comes through spoken language, or picture cards, a communication device, gestures or sign language; it is all communication. Each child has something to say to us. It is our responsibility to listen in a way that ensures that they are heard and understood, which can be done with the help of a speech and language pathologist.

You as a parent spend most of your time with the child, thus it will be very useful if you could get trained and adequately guided from the therapist and perform the therapy for your child on your own. It is important for the parents and teachers to put a daily and regular effort in improving the speech and language development of the child. Your child may have problems with verbal or nonverbal communication. Accordingly, you can adapt certain strategies to improve the speech of your child. Generally improvement in speech takes time. Thus, the parents need to understand that they need to continue their efforts in the right direction, which will surely lead to improvement in their child.

An eight-level hierarchy of supports makes it possible to build the foundations for voice and articulated speech. This hierarchy will help you understand that, if the child is unable to speak it does not mean he cannot communicate. It only means that, a step wise process is needed to be followed to help the child on the spectrum to find his words.

Level 1 - Deep breathing/ exhalation.

Level 2 - Voice/ vocal production.

Level 3 - Intonation

Level 4 - Starting, maintaining, and stopping sound.

Level 5 - Vowel sounds.

Level 6 - Consonant sound development.

Level 7 - Sequencing words.

Level 8 - Purposeful speaking.

The detailed description of each of these levels is described in the section of speech therapy. A speech and language pathologist will help identify at what level your child is and take him through each of these levels with the help of appropriate techniques. They also help assess communication skills and develop an appropriate program to improve them, often using an alternative or augmentative communication strategy.

- **If your child acquired speech and lost it eventually:**

- Your child may have had speech before and eventually lost it. Use flash cards or pictures to explain simple action verbs like standing, sitting, sleeping, smiling, crying, laughing, playing, bathing, eating, etc. which would be helpful for him to communicate his needs.
- Identify commonly used nouns i.e. objects (light, fan, table, chair, door etc), fruits (which the child eats), vegetables (those which are commonly prepared at home), common animals, basic colors, basic shapes, etc.
- Picture cards and real objects are important because visual, auditory, tactile stimulation help children to understand concepts faster. You need to follow a similar pattern for first matching, then recognition of a particular shape or object.

- **Has difficulty in using non-verbal language or gestures to communicate:**

- **Improve eye contact:**

- Visual (sight) and auditory (sound) stimuli can be used to improve eye contact. This can be done by moving flickering lights in front of the child's eyes. You need to demonstrate to the child as to how he can track the light with his eyes. Reinforce this behavior by giving the child things he likes in small quantity. Regular practice is necessary to increase the duration of eye contact. For example, ask the child to track a light or sound stimulus (torch, bell, mobile phone etc.) from top to bottom or even from left to right side. Place an eatable or candy at the end point. If your child wants to eat, he must track the light or sound stimulus from top to bottom.
- Hold some glittering object near your eyes and encourage child to look in your eyes. This can also be practiced by making it compulsory for your child to look into your eyes while being fed.
- Recognition and use of facial expressions
- Posters or picture cards demonstrating all these facial expressions along with associated situations leading to such expressions can be useful. For example, receiving a happy smiling face after completing a task and receiving an angry face card after breaking a vase can be used to teach the child facial expressions.

- Give the child a visual as well as auditory stimulation i.e. show the cards to the child and ask him to imitate the expressions with verbal explanations. Carry out this task every time a particular expression is required of him/her.
 - Click a picture of your child whenever he/she gives an expression and associate it with a particular situation. Replace the picture cards with these pictures of your child. Try to make it as realistic as possible because children do not understand abstract things.
- **Body gestures and posture :**
 - Every time your child meets a person, encourage him to shake hands and say "hello". When he does that, appreciate his behavior with adequate reinforcement. For example, give a sticker, star, chocolate etc.
 - Give him/her a hug whenever he does something good or puts up a good behavior. Similarly encourage him to wave good-bye when somebody takes a leave. These body gestures are very important which child has to learn.
 - Multi sensory stimulation facilitates communication. Like showing a picture, demonstrating to the child how to wave "goodbye", letting the child listen to the tone, feel the inflation in voice and observe the facial expressions will help the child imitate. Video recording these gestures and playing it repeatedly for the child will provide good feedback.
 - **Head turn response to a name call :**
 - Lay out several photographs of their own in front of them. Let the child identify his/her photo from a bunch of random photographs. Ask them to point at the photograph and then to self, each time.
 - Similarly, teach them to recognize you in the photographs. Ask them to match the person in the photographs to the actual person i.e. you as a mother or father. This can then be extended to other family members, thus improving self-recognition, visual image and associations.
 - Once child learns to recognize visually, shifting to the auditory (name call) mode is easy. For example, if your child's name is Amit, ask him "Can you find Amit's photo for me? Where is Amit in these photographs? Yes that's right. This is Amit (pointing at the photograph and then at him)."
 - **Attention and concentration :**
 - Coloring or scribbling activities, joining dots, pattern drawing etc. can be attempted.
 - Thumb painting, finger painting, painting using different shapes like lady's finger dipped in color and stamps, sponges of different shapes can also be used.
 - Paper folding activities, Origami (craft activity with paper) can be helpful. Give your child paper to make small bits or paper balls by tearing it and then putting them into a box. Later, ask him to glue the paper pieces and paste on

a chart paper to make a collage design. Color papers, use of sparkles etc can make the activities interesting. Encourage and appreciate creativity.

Engages in stereotyped and repetitive use of language/Engages in echolalic speech:

- To tackle echolalia (repetitive speech) the child needs to be diverted through some constructive activity so that child's attention gets diverted. Do not respond to your child's verbal repetitions by saying "don't say that" or "stop it". Instead, just give the child an activity he enjoys. For example, water activity, dance, music etc.

Unable to initiate or sustain conversation with others:

Speech of a child with autism comprises mostly of non-meaningful words or repetitions of words or phrases. To have your child use meaningful words for expression and responses is a complex task.

- To achieve this, first encourage your child to vocalize maximally. For example, make him say /a/, /e/, /u/, /pa/, /ba/, /ma/, /la/, /ka/, /ta/, /da/, /na/, etc.
- Show him the tongue and lip placement for producing the above mentioned syllables. If required help your child in closing his lips to produce sounds of /pa/, /ba/, /ma/. This way the child will learn the correct manner of producing a particular syllable.
- Once the child produces any of the above syllables, help him/her use those syllables to communicate, for example, requesting for food, water etc.
- The next stage is combining two syllables like /mama/, /papa/ and saying it aloud every time he sees you (mother or father). In this way syllables can be combined to make a word production.
- Initially, encourage all kind of verbal production; later, try to shift towards meaningful words.
- While talking to your child, speak loudly and clearly using intonation. Open your mouth wider so that the child can see tongue and lip movements for imitation. When your child attempts to imitate, reinforce the positive behavior with a toy or an eatable.

Uses jargon or meaningless words/Uses pronoun reversals/ Unable to grasp pragmatics of communication (real meaning):

- Use of picture cards, Prepositions like on, under, above, inside, outside, up, down, left, right, front, back are also difficult for these children to comprehend. This is not only because they do not understand the language rule but also due to their poor orientation abilities. Hence, a more practical approach is necessary to teach prepositions. For example, keep things that your child recognizes by name (a soft toy) at different positions- to his left/ right, above the bed, under the bed, etc., and ask him to look for it. Focus on and repeat practice for a particular preposition along with verbal prompts, visual clues so that child can locate faster

- Understanding and learning the use of adjectives independently is difficult for the child due to its abstractness. Yet, simple adjectives like good, bad, beautiful, dirty etc. can be worked upon by using picture cards and also with extensive use during communication with the child. Once achieved, these adjectives can be used as reinforcers as well. But it must be remembered that adjectives are understood much after nouns, verbs and prepositions. Talking extensively and with overemphasis helps recognition of common nouns and adjectives.
- Say things in the order/ sequence in which they will happen.
- Repetition can help with memory, as can visual clues. It is often easier for someone to remember something if they have a picture to go with the instruction.

There are certain medications which can help as an adjunct in improving the child's speech. These include Sertraline for overall improvement in development of language, Folic acid supplementation, Acetylcholinesterase inhibitors like rivastigmine, donepezil, and galantamine, glutamate antagonists like Memantine and Dimethylglycine (DMG). It is advisable to consult your doctor regarding the use of these medications, to see which medication suits best for your child. Other therapies which are useful in improving communication and social skills in children with autism include Art and Music therapy. The detailed discussion of all the activities which you can perform with your child along with the speech therapist is given in the section of speech therapy. Assistive devices like Speech Generating Devices (SGD) and Voice Output Communication Aids (VOCA) can be useful for these children in order to communicate with the caregivers efficiently. The detailed description is given in the section of assistive technology.

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14. Sensory Aspects

Integration of various senses makes it possible to use our body effectively in response in the environment. Children with autism are believed to have difficulties receiving, assimilating, integrating and processing sensory information. Withdrawing when being touched, refusing to eat certain 'textured' foods and/or to wear certain types of clothing, disliking having one's hair or face washed, avoiding getting one's hands dirty (i.e., glue, sand, mud, finger-paint), and using one's finger tips rather than whole hands to manipulate objects are some signs of problems with the sensory system of the child.

Sensory integration therapy is a type of occupational therapy intervention that places a child in a room specifically designed to stimulate and challenge the senses. During the session, the therapist works closely with the child to encourage appropriate productive and adaptive movement responses. Sensory integration therapy is based on the assumption that the child is either over-stimulated or under-stimulated by the environment. For example, your child may not like to get his hair or nails cut, he may dislike messy objects or food items and may be aversive to touch or hugs from people. This indicates a low threshold for touch stimuli making him hypersensitive/ over-stimulated. On the other hand there could be another child who actively goes and hugs and touches even strangers, who likes playing with fabrics or different textured materials, or mouths all objects. Such a child is hypo-responsive/ under-stimulated due to which he constantly seeks tactile inputs to meet his/her high threshold levels. Therefore, the aim of sensory integration therapy is to improve the ability of the brain to process optimal sensory information from his body and surroundings, so that the child will function better in his daily activities.

Following are some of the activities which you can perform with your child, if he/she has any of these symptoms.

- **If your child is unusually sensitive to sensory stimuli:**

In this case, you need to desensitize the sensory system, mainly the tactile (touch) system. You can encourage bear hugs, back scratch, massaging with/without lotion,

oils, exploring various textures, using foamy soap/shaving cream. You can also encourage use of different daily objects which are modified to desensitize their hypersensitivity like vibrating objects including toothbrush, pens, balls, stuffed toys, etc. "Sandwiching" between pillows, climbing under sofa cushions also aids in desensitizing the overly active sensory system.

- **Stares into space for long periods of time and has difficulty in tracking objects:**

Work on improving his eye contact and sustaining his vision, which is explained in the section of social relationship and reciprocity, as it is the basic foundation in improving the function of visual system. You can encourage tracking of different objects by looking at photos, picture books, looking at fish tanks, farm, zoo, and ocean. Watching cartoons and movies of his/her choice would also enhance the sustenance and tracking of vision.

Modify the interiors wardrobe and toy section of your child, to his preferred color scheme, themes clothing texture, objects etc. to get maximum cooperation from your child.

- **Has unusual vision:**

Avoid complicated prints and patterns on clothing, walls, and floors. Encourage looking at mobiles, lava lamps, bubble lamps, disco globes, colored rotating discs, colored light bulbs

- **Insensitive to pain:**

Being insensitive to pain indicates a hyposensitivity or hyporesponsiveness of his/her tactile system, which is responsible for interpreting various touch sensations. These children need to be sensitized to various sensations like hot and cold, fine and rough textures, etc. as it can be potentially dangerous for the child, as he cannot perceive the sensation. Activities like scrubbing with washcloth/scrubby, wearing different fabrics, use of sensory bin with dry rice & beans, grains or other materials and use of warm towels/cloth with blow dryer after bath can be worked with them at home.

- **Responds to objects/people unusually by smelling, touching or tasting:**

- Use of essential oils and scented candles, exploring tastes: sweet, salty, sour, spicy, bitter, smelling flowers, sniffing spices and herbs and playing blindfold smelling games can help him understand and relate the sensations with respect to objects and people.

Sensory system plays a very important role in connecting and responding to a person's environment. With all the above activities, you should be able to perform sensory motor integration therapy with your child in an effort to alleviate his sensory symptoms and making him and his environment more conducive. Other therapies which are good adjuncts in targeting sensory issues include art and play therapy. The detailed discussion of all the activities above is explained in the section of Occupational therapy.

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15. Behavior Patterns

Obsessions, repetitive behavior and routines can be a source of enjoyment for people with autism, and a way to cope with everyday life. But they may also limit people's involvement in other activities and cause distress. Here are some of the relieving activities/medications which you can incorporate, if your child exhibits any of these problems.

- Arrange situations for the child in such a way that he will be required to find clues to ascertain how someone is feeling or to predict how they might respond. He or she needs to be taught about various facial expressions, emotions and how sounds, tones or voices of people change for every emotion.
- Use videotapes or television to reinforce learning about facial expressions and sounds of emotions
- Use stories with that have a moral or message and narrate them in a step by step manner which would help him/her understand the behaviors that are acceptable socially

Engages in stereotyped and repetitive motor mannerisms:

If you can help your child to identify when they are feeling stressed or anxious and use an alternative response (such as relaxation techniques or asking for help), you may, in time, see less repetitive and obsessively habitual behavior. Research has also shown that increasing a person's insight into an obsession or repetitive behavior can significantly reduce it. One way to interrupt repetitive behavior is for a child to do another enjoyable activity that has the same function. Here are some examples:

- A child who rocks to get sensory input could go on a swing
- A child who flicks their fingers for visual stimulation could play with a kaleidoscope or a bubble gun
- A child who puts inedible objects in their mouth could have a bag with edible alternatives (that provide similar sensory experiences) such as raw pasta or spaghetti, or seeds and nuts

- **Shows attachment to inanimate objects:**

Obsessions can be used to increase your child's skills and areas of interest, promote self-esteem, and encourage socializing. You may find you can look at a particular obsession and think of ways to develop it into something more functional. Here are some examples.

- An obsession with computers could be developed into someone studying or working in IT.
- A person with a special interest in historical dates could join a history group and meet people with similar interests.
- A person with knowledge of sport or music would be a valuable member of a pub quiz team.
- An obsession with rubbish could be used to develop an interest in recycling, and a child given the job of sorting items for recycling.

- **Shows hyperactivity/restlessness:**

- While many of the strategies are things a parent can do to help their child, it is also important to teach your child methods for self-regulation. Deep breathing exercises, yoga, or meditation all help a child learn to slow down their thoughts and their bodies. Work with a professional if you aren't sure how to teach your child these different methods of relaxation.
- Hyperactivity zooms when boredom sets in. Create a box of activities geared toward your child's interests. The box might contain dress-up clothes, art supplies, Legos, models or whatever activity tends to hold your child's interest. To keep the box interesting and novel, switch items once in awhile and once he has lost interest, put the box away until it is needed again.
- Soothing music, such as classical music, can help some children calm down. Experiment with different types of music to find out what works for your child. Use music in the background for times when activity levels should be low, such as homework time, dinner time or before bedtime
- Children react to your reaction. If you get upset, frustrated or angry, their hyperactivity levels may increase. Take a few deep breaths, go into the other room, and take a short break if you need one. Staying calm and reacting with a neutral voice will help your child remain calm.

- **Exhibits aggressive behavior and engages in self-injurious behavior/ Throws temper tantrums:**

Children on the autism spectrum find it difficult to manage their feelings. An important skill to be learnt by a child with autism is to monitor and manage their emotions and behaviors. This would equip them to identify and respond appropriately to situations, which in turn could increase independence and confidence. Below are listed few strategies to manage the emotions and aggression in your child:

- Encouraging / helping them communicate their feelings and emotions verbally.
- Other ways of displaying their emotions; for example, if a child is angry then he should display it by punching the pillow rather than hitting others around or biting himself.
- Use of "time-out" by immediately isolating the child for a short period of time is an effective measure to allow you and the child to cool down
- Constructive and acceptable ways to vent out physical or verbal aggression should be taught; for example playing the drums, painting, coloring, playing competitive sports, or dancing to energetic music, etc.
- Identify the physical behaviors that indicate that they are agitated or angry and develop a range of alternative, more appropriate activities that help them calm down. These can include breathing exercises, counting exercises, going for a walk, listening to music, walking away from the scene or asking for help. The child should be helped to develop the communication skills needed to express his distress and request for help.
- If your child is throwing temper tantrums or is behaving aggressively in public, shouting at the child or correcting the child in front of other people wouldn't be a good idea. Rather, the best possible solution would be to leave the place as quickly as possible and finding ways for your child to cool down.
- Teach the child breathing exercises. Help him understand when to use it and practice it, so that the child is equipped to use it when he is stressed and anxious.
- Exercise and play sessions are extremely important for the child, as it would help him relieve stress.
- Self-talk method (communicating to one self and evaluating one's own feelings) should be taught to the child. This should be practiced only when he / she is alone in the room.
- Maintaining a STAR chart. It is a helpful way of assessing what happens before, during and after an episode of unacceptable behavior. It helps reduce the behavioral problems that many parents like you face. Detailed description is explained in the chapter of psychological intervention.

- **Insists on sameness:**

Many children have a strong preference for routines and sameness. Routines often serve an important function - they introduce order, structure and predictability and help to manage anxiety. Because of this, it can be very distressing if a person's routine is disrupted. Sometimes minor changes such as moving between two activities can be distressing; for others big events like holidays, birthdays or christmas which create change and upheaval, can cause anxiety. Unexpected changes are often most difficult to deal with.

- A visual timetable could help your child to see what is going to happen next (for example, across the course of a day). This makes things more predictable and helps them to feel prepared. It may lessen their reliance on strict routines of their own making.
- You may be able to help your child to cope with change, or activities and events that could be stressful, by planning for them in advance.
- Change is unavoidable but it can be really difficult for many people with an ASD. You may not always be able to prepare for change a long time in advance, but try to give your child as much warning as possible. Gradually introducing the idea of a new person, place, object or circumstance can help them cope with the change. Try to talk about the event or activity when everyone is fairly relaxed and happy.
- Pre-planning can also involve structuring the environment. For example, a pupil with an ASD might go to use a computer in the library at lunchtime if they find being in the playground too stressful. Or if a child has sensory sensitivity, minimizing the impact of things like noises (e.g. school bells) or smells (e.g. perfumes or soaps) can help them to cope better

Other therapies which may help in improving behavior patterns in a child with autism include Dance therapy, Music therapy and Animal Assisted Therapy. There are certain medications which can help reducing your child's behavioral symptoms. There can be classified as prescription and non prescription medications. Prescription medications include Risperidone, Tricyclic Antidepressants (TCAs) like Nortriptyline and Desipramine and stimulants such as methylphenidate, amphetamine, and dextroamphetamine which helps in regulation of the dopamine levels in the brain. Non prescription medications include Vitamin B12, vitamin C, combination of Vitamin B6 and Magnesium and Omega-3. It is extremely important to consult your doctor before starting your child on any of these medications.

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SUMMARY :

A child with autism displays a wide range of illnesses with psychological and organic etiology. The symptoms occur most frequently when a child has been forced, from infancy or an early age, to live and to grow in his own private world due to severe perceptual or intellectual difficulties. If the symptoms of autism are anticipated, diagnosed, and treated early, then the child may develop in a relatively healthy and productive way. Without an appropriate treatment the symptomatic autistic child is liable to be increasingly handicapped, eventually such a child is almost indistinguishable from children who are autistic due to other causes. Hence it is extremely important to treat the symptoms of the child as early as possible which will eventually help the child in reducing his level of dependence and thus leading an improved quality of life.



SECTION D

Multidisciplinary Approach for Autism



A Multidisciplinary Treatment Approach

Multi-disciplinary team approach to management

As parents, you may frantically look for all possible treatment options for your child. Your search may give you several options which may further confuse you or create more doubts. With help from your developmental pediatrician, you may be able to identify the problems in your child and decide about the early intervention plan. Early identification has increased in importance, as many studies have found that children with ASDs who receive services prior to 48 months of age make greater improvements than those who enter treatment programs after 48 months of age. Management in autism calls for a Multi-disciplinary holistic approach. You will probably be referred to a psychologist, an occupational therapist, speech and language pathologist, dietician etc. Each of the above professionals will target different aspects in the treatment of your child. It is important to understand that intervention is not exclusive i.e., there are several aspects that may overlap. Therapists working with your child must synchronize the goals and approaches so that the child does not get confused and therapy moves in a single direction. This section provides a detailed understanding of the interventions provided by each of these professionals and methods by which you could apply them for your child at home/ school.



Figure 10.1: A Multi-Disciplinary Approach

16. Medical Management

"What should we do next? Are there any medicines to cure autism...? If not a cure, what is the role of medications in treatment of autism? When should one consider the use of medicines? If required then what are the different types of medications used in autism? How do these medicines work? And what are their beneficial effects in autism? Are there any specific indications and contraindications? Are there any risks or sideeffects of medications? And if medicines are started, how to monitor for the side-effects ? Can we verify the effectiveness of medications in a particular individual ? Is there any benefit of using over the counter / herbal / non-prescription medicines? Do combination therapies offer any added advantage? Are there any clinical studies to support the use of medicines? How much do we really know?"

These are some of the common queries that arise in the minds of the parents of children diagnosed with autism. In this Chapter, we will discuss various viewpoints to address these issues and try to clarify any doubts.

Until now there are no medicines available to cure autism. All the medicines provide only symptomatic relief. However, treatment of symptoms is very important as it is the distressing symptoms that limit the quality of life of people with autism, their families and caregivers. Once the symptoms are controlled with medications, there is a better scope for benefit from multidisciplinary interventions like Occupational therapy, psychological therapy, speech therapy, vocational training, etc.

If you suspect your child to have any symptom of autism then consult a doctor immediately as early diagnosis and therapy intervention may improve the long term outcomes. If the diagnosis is confirmed and the symptoms are mild then intervention in the form of various therapies must be tried as a first option. If the symptoms are severe and difficult to manage or; have the potential for self harm or; pose a threat to surroundings/people or; cause major familial distress or; affecting daily functioning or schooling, then use of medicines should be considered. There are various medications being used for control of diverse symptoms in autism. Here we discuss the commonly used medicines. Largely medications can be divided into prescription and nonprescription medicines.

- **Prescription medicines**

There are only 2 drugs that are US FDA approved for autism- Risperidone (Risperidal) and aripiprazole (Abilify). Therefore the use of other medications is known as "off-label". This means that the medications are established and approved by FDA for other disorders but not specifically for autism. The rationale behind the "off-label" use is that if a medicine controls a particular symptom in one disease, then the same mechanism of action can be extrapolated to the management of the same in autism. But, further research is required to ensure the safety and efficacy of these "off-label" medications.

The most commonly used prescription medicines are as follows:

1. ***Antipsychotic drugs***

Antipsychotic drugs are categorized into the older conventional (typical) drugs (Haloperidol and Chlorpromazine) which are associated with many side-effects and the newer generation (atypical) drugs. Among the atypical antipsychotics, Risperidone and Aripiprazole are the only two US FDA-approved medications for ASD. They have been recommended in the treatment of irritability only for the age group of 5 to 16 years. They are used to treat irritability that is associated with behavioral problems like aggression, self-injury, temper tantrums and mood swings.

Risperidone acts by blocking the neurotransmitters [chemical substances which carry signals across nerve connections] serotonin and dopamine, which have been found in abnormal levels in many individuals with ASD. Four randomized controlled trials (RCT) of Risperidone in autism have been conducted. Two of the studies targeted challenging behavior and results were measured by Aberrant Behavior Checklist (ABC). Improvements in hyperactivity and repetitive behaviors were significantly greater for subjects in the Risperidone group as compared to the placebo group in both the studies. One study recorded improvements on the CARS scale. The fourth RCT used a variety of assessment measures to show beneficial effects of Risperidone in autism. The most common side effects of Risperidone include drowsiness, constipation, fatigue and weight gain. In some individuals serious side effects like extrapyramidal symptoms (tremors, dyskinesia, rigidity and tardive dyskinesia), neuroleptic malignant syndrome, hyperglycemia and diabetes have been observed

Aripiprazole works on the dopamine receptors and was approved in November 2009. (It is available as 2mg and 5mg tablets). Two RCTs were done of Aripiprazole in children with ASD. Improvements were noted on ABC. Both the trials reported improvements in repetitive behaviors. The side effects profile of Aripiprazole is similar to that of Risperidone.

Due to the side effects of Risperidone and Aripiprazole routine monitoring of body weight, waist circumference, blood pressure, fasting sugar levels and fasting lipid profile are recommended.

Other Atypical Anti-psychotics (Clozapine, Olanzapine, Quetiapine and Ziprasidone) : There are few reports of Clozapine used to reduce hyperactivity and aggression in individuals with autism but it is not widely used because of adverse effects on blood counts and seizure threshold. Ziprasidone has some beneficial effects in autism and is devoid of any significant weight gain or other adverse effects. Its use is limited by the lack of clinical studies.

If your child has difficult to control aggression, self-injurious behaviors, temper tantrums, repetitive behaviors or quickly changing moods consult your doctor for advice on this group of medications.

2. *Antidepressants*

Primarily, antidepressants are widely used for the treatment of depression, anxiety and obsessive compulsive disorder. These symptoms may be seen associated with ASDs. Hence, this group of drugs can be extrapolated for the use in ASDs. It has been studied for its potential to treat repetitive and problem behaviors in autism. They are broadly classified into TCAs (older) and SSRIs (newer) and they work on the neurotransmitter serotonin. Persistent reports of elevated platelet serotonin levels in nearly one third of children with autism have been documented. Several researchers believe dysfunctional serotonin signaling to be a causal mechanism for the disorder. Today, SSRIs are used more widely as the TCAs are associated with several side effects.

Selective Serotonin Reuptake Inhibitors (SSRIs): This group includes drugs namely Fluvoxamine, Fluoxetine, Citalopram, Escitalopram and Sertraline. Treatment with these medications may help decrease frequency of repetitive, ritualistic behavior and improve eye contact and social interaction.

A controlled trial in autism reported the significantly greater effect of Fluoxetine treatment over the placebo on the Yale-Brown compulsion subscale and Clinical Global Impression scale [CGI]. Apart from overall improvements seen on the CGI scale, reductions in repetitive behaviors and obsessive-compulsive symptoms were also reported. The medication was tolerated well with no side effects reported. Recently, another controlled study compared and analyzed the effects of Fluoxetine and Fluvoxamine. While both were shown to be effective in reducing repetitive behaviors it was identified that children with autism tolerated Fluoxetine better than the available doses of Fluvoxamine. In adults, Fluvoxamine was better tolerated and more beneficial for the repetitive behaviors. Thus, Fluvoxamine may not be a first choice in children with autism.

No significant benefits were noted with citalopram and escitalopram in controlled studies. Sertraline has shown some potential to improve language development.

Side effects of SSRIs include anxiety, insomnia, GI disturbance, appetite and weight changes, mania or hypomania. Suicidal ideation has not been reported as a possible side effect in studies on SSRIs in autism. SSRI-induced activation

and agitation, in few children warrants closer attention to dosage, titration, and subject selection.

Tricyclic Antidepressants (TCAs): This group of drugs includes Nortriptyline, Amitriptyline, Clomipramine, Desipramine, and Imipramine. Nortriptyline has been found to be effective in children with ASD. Studies have reported improvements in hyperactivity, aggressiveness, and ritualized behavior. Imipramine was not well tolerated by children with autism. A controlled trial comparing Clomipramine to a placebo found that 58% of the individuals with autism responded better to Clomopramine. Another study showed the adverse effects of Clomipramine to include sedation and worsening of symptoms like aggression, irritability, and hyperactivity. Desipramine was shown to improve autistic symptoms, anger and compulsive and ritualized behaviors.

Other antidepressants used in autism: Venlafaxine has been reported to improve restricted behaviors, interests, social deficits, hyperactivity and communication problems in individuals with autism.

3. *Stimulants*

Drugs such as methylphenidate, amphetamine, and dextroamphetamine that act on the dopamine system are primarily used to treat hyperactivity and inattention in patients with attention-deficit hyperactivity disorder (ADHD). Methylphenidate is presently approved by FDA only for ADHD. Since these ADHD like symptoms are found to be present in many children with autism, stimulants may be useful in them too. Symptoms like inattention, hyperactivity and impulsivity can be addressed by these medications.

RUPP Autism Networks's trial of methylphenidate demonstrated superior effects of the drug as compared to the placebo. Beneficial effects were recorded in 50% of the patients on ABC and CGI scales. A review of controlled trials concluded that Methylphenidate may be effective to reduce ADHD-like symptoms in persons with PDD or ASD. Trials investigating the effects of Methylphenidate reported adverse effects like appetite reduction, sleep-onset difficulties, irritability, emotional outbursts, anxiety, depression, headache, and diarrhea. Other psychostimulants used in children with autism include Amphetamine mixed salts and Dextroamphetamine.

Some children with autism could benefit from the use of psychostimulants if they tolerate the side effects. The specific target group for which the drug may be best suited, is yet to be identified for autism. These drugs can be considered under the guidance of a doctor, for increased hyperactivity and poor attention span.

4. *Mood Stabilizers*

This group of drugs is commonly used to treat bipolar disorder in both children and adults. Other uses include the treatment of behavioral symptoms such as aggression, self-injurious behaviors, impulsivity and conduct disorder.

Mood stabilizers possibly used include lithium, lamotrigine, valproic acid, carbamazepine, topiramate, oxcarbazepine and levetiracetam. Many anti-seizure medications have mood-stabilizing properties as well. Only a handful of these drugs have been studied in children with autism and definitive, reproducible results are not available. These medications are generally used on a case-by-case trial basis. It is less used as a mood stabilizer or for behavioral symptoms in children with ASD. Those found to be effective in seizure management are used as anticonvulsants in children who have ASD with seizures.

5. *Anticonvulsants*

Outside ASDs, anticonvulsants are usually prescribed to control seizures. Many a times autism is associated with seizures. Anticonvulsants commonly used in autism are phenytoin and sodium valproate. Incidentally, studies pertaining to autism have shown divalproex sodium to produce clinical improvements in the various core symptoms such as receptive language, affective instability, aggression, and social skills. Researchers also found levetiracetam to be useful in reducing hyperactivity, impulsivity, aggression, and affective lability. Thus, anticonvulsants appear to alter the core symptoms of autism but through which mechanism is yet unknown. Side effects of these drugs are a major concern. Routine liver function tests should be performed before and during treatment. Monitoring the drug levels through regular blood tests becomes necessary.

6. *Glutamate antagonists*

Researchers have identified excessive glutamate levels in postmortem brain samples of some individuals with autism. Normal glutaminergic activity is essential for long term learning and memory functions. Dysregulation between the excitatory and inhibitory systems has been found to have a causal role in autism. Thus studies have been conducted to investigate the usefulness of glutamate antagonists in autism such as amantadine, memantine. In a randomized double blinded placebo controlled trial, amantadine has been found to be beneficial in reducing hyperactive behaviors and inappropriate speech in children with autism.

Memantine, a NMDA receptor blocker, is widely used for the treatment of Alzheimer's disease (AD). Calcium flux through the NMDA receptor, a glutamate receptor, is of importance in controlling synaptic plasticity and memory functions. The use of memantine in treatment of autistic individuals has been associated with the improvements in memory, hyperactivity, irritability, language, social behavior and selfstimulatory behavior. Few patients were reported to have experienced adverse effects like worsening of autistic behaviors.

Two recent small open-label studies have reported the beneficial effects of memantine on improving language and behavior of individuals with autism.

Another large scale clinical trial study observed that use of memantine significantly improved language function, social behavior, and self-stimulatory behaviors. A study reported improvements on the CGI-I in few persons with Fragile X syndrome (FXS) and a diagnosis of pervasive developmental disorder (PDD). However, the cellular mechanism by which memantine improves language and social behaviors in autism remains unclear. There are ongoing registered trials investigating the effects of memantine in autism.

7. *Acetylcholinesterase inhibitors*

Studies have described deficits in brain cholinergic function in some individuals with autism. Hence, research has examined the use of acetylcholinesterase inhibitors, including rivastigmine, donepezil, and galantamine, in children with ASD. The use of rivastigmine autism led to significant improvements in overall autistic behavior. Some of the adverse effects included nausea, diarrhoea, hyperactivity and irritability. Donepezil has also been reported to improve irritability and hyperactivity in children with autism. Galantamine produced significant improvements in irritability, hyperactivity, social withdrawal, inappropriate speech, inattention, reduction in anger and autistic behaviors.

Other medications with CNS effects used in ASD include alprazolam, buspirone, lorazepam, naltrexone, diazepam, melatonin and antihistamines. Naltrexone has also been identified to have significant improvements with respect to self-injurious behavior, hyperactivity, social withdrawal, agitation and irritability in autism spectrum disorders.

8. *Other groups*

Clonidine an alpha blocker used in the management of hypertension has been shown to help improve hyperactivity, mood instability, aggressiveness and agitation in individuals with autism, with largely tolerable side effects. A placebo-controlled doubleblind clinical trial of clonidine in autism provides support for the clinical efficacy and safety of clonidine in autism and related disorders. A study also reported improvements in sleep, night time awakenings, aggression and mood with bedtime doses of Clonidine. Another retrospective study on the use of guanfacine provided with evidence of improvements in attention, hyperactivity, insomnia, and tics. The most common adverse effects reported with guanfacine were insomnia, fatigue, blurred vision, headache, and mood alteration.

Gastrointestinal agents

In children with ASDs the GI system has been identified to have associated problems. An irritable or inflamed gut can further increase the core symptom severity. Thus the GI system is specifically targeted by medications in some children. Medications are prescribed based on their effectiveness in treating the particular target symptom like

chronic diarrhea, constipation, or acid reflux disease. The possible effects of these drugs on the overall functioning of the child are not yet established.

Secretin a gastrointestinal agent produced naturally in the intestines has been extensively studied for the treatment in autism but is now disproven. Secretin has been studied by over 14 randomized controlled trials. One of the earliest studies reported that Secretin had positive effects on the behaviors associated with autism. It was only later that the scientific community confirmed that there was no evidence that secretin was beneficial for treatment in ASDs.

Other GI medications reportedly used in children with ASD include antacids; namely famotidine and bethanechol; and probiotics. Probiotics are microorganisms that are said to improve digestion. They help in the removal of toxins and enhancing the immune functions in the body. Many children with autism are reported to have associated GI problems. There are no trials providing evidence for effectiveness of probiotics in ASD. They are believed to decrease self-stimulation and stereotypies, aggression, GI symptoms, hyperactivity and improve socialization. Probiotics are indicated in children with ASDs having GI problems. There are no reported side effects nor any published evidence.

Arbaclofen

The drug, known as arbaclofen or STX209, is a derivative of the FDA-approved drug, baclofen, which is primarily used to treat muscle spasticity. It is an experimental drug with promising results in treating the key symptom of social withdrawal in people with Fragile X syndrome, the most common known inherited cause of autism with intellectual disability. A recent study published in Science Translational Medicine, indicates that arbaclofen could be the first drug to treat symptoms of Fragile X and other autism spectrum disorders. It may also be used in other conditions involving social avoidance.

Immunological agents

Research continues to investigate the relationship between the immune system and the symptoms of ASD. Autoimmunity and immune dysfunction has been recently implicated as an underlying mechanism in ASD. Associated problems like allergies, infections are a common finding in children in autism. In addition to these abnormal laboratory values have been reported in relation to the functioning of the immune system. Therefore, medications that alter the immune system are actively being used in children with autism. Immunologic therapies used in children with ASD include intravenous immunoglobulins (IVIG), anti-viral medications, anti-fungal medications and steroid therapy.

There are six published open-label trials of IVIG treatment in ASD. Only one study found benefits with respect to language and behavior. Due to its potential risks IVIG is not highly recommended. Hence, other safer immune therapies need to be explored.

- **Non- prescription medicines**

1. ***Omega-3***

Omega -3 is a group of essential fatty acids [ALA-alpha-linolenic acid, DHA docosahexaenoic acid, EPA- eicosapentaenoic acid] which play an important role in the functioning of the brain. Substantial evidence has indicated the association between deficiency or imbalance of essential fatty acids and childhood neurodevelopmental disorders. Omega-3s are also implicated in reducing inflammation, which may improve immune functions in ASD. The ratio of omega -3 to omega 6 is reduced by the modern diet. Fish oil is a rich source of omega -3. Flax seed and plant sources of omega-3 provide ALA which is partially converted to EPA and DHA. Algae oil mainly contains only DHA. The deficient intake of omega 3 fatty acids has been co-related to symptoms such as aggression, impulsivity, attention deficit and hyperactivity seen in children with Autism Spectrum Disorders (ASDs). In some children, dietary supplementation with fish oils (providing EPA and DHA) has shown to diminish ADHD-related symptoms. A study also found improvements in academic achievement with omega -3. A few other studies with Omega-3 supplementation showed improvements in cognitive and motor skills, concentration, eye contact, sociability and sleep, along with reduction of hyperactivity, repetitive behavior and aggression. It is thus indicated for stereotypical behavior, hyperactivity and inappropriate speech. There are no reported side effects. No large clinical trials are available to ensure the safety and efficacy of omega -3.

2. ***Combination of Vitamin B6 and Magnesium***

High doses of vitamin B6 was amongst the earliest supplementation to exhibit beneficial effects in autism. Magnesium was added to tackle the side effects of higher doses of B6. A combination of these two essential nutrients is presumed to correct a metabolic aberration. This requires a higher than usual intake. While there are encouraging results of their efficacy in open studies, randomized controlled trials have been less promising. Studies have reported improved alertness, social interaction, communication and reduced outbursts, negativism, self-mutilation, and stereotyped behavior. The combined intake has been implicated for improving social interaction, communication and repetitive behavior. It is said to lead to neuropathy and diarrheas with doses higher than 200 to 300 grams. It is under the acceptable category of drug recommendation.

3. ***Injectable Vitamin B12 (methylcobalamine)***

Individuals with ASDs may be associated with deficiency of vitamin B12 due to poor dietary intake, poor absorption, or metabolic abnormalities. This can lead to decreased antioxidant capacity. Antioxidants are essential for the protection of our cells against the damaging effects of free radicals. Only one published study in children with autism suggests vitamin B12 to be ineffective in treating the

behavioral symptoms. However some symptomatic relief was seen in a subgroup of children. Additional research in this area is warranted. Since it is administered via injections, it falls under the not recommended category of drugs.

4. *Folic acid*

It is a known fact that folic acid is essential for appropriate brain development. Folic acid gene abnormality doubles the risk of autism. An open trial of folic acid and B12 in children with ASD and antibodies to the cerebral folate receptor showed significant improvement in receptive and expressive language. Research provides us with insufficient data about the improvements specifically in ASD. The use of folic acid is indicated in individuals with problems in receptive and expressive language. No side effects have been reported. Its safety, ease of administration and low cost place it under the recommended category.

5. *Vitamin C*

Vitamin C is a known antioxidant which prevents oxidative damage in brain. It helps improve cellular immunity and also influences the activity of neurotransmitter, dopamine. This can possibly help reduce the metabolic stress. This provides the basis for its use in autism. It is indicated in children with repetitive behavior. One double blinded randomized controlled trial showed a decrease in stereotypical behaviors. Side effects were reported when large doses [90 mg/kg] were used. These high doses may interfere with vitamin B12 absorption and hence are not recommended.

6. *Iron Supplementation*

Iron deficiency has been identified in some individuals with autism. This may be associated with psychomotor retardation, poor sleep, and neurological and behavior problems. It is indicated in children with restless and disturbed sleep. An open trial studied oral iron supplementation that resulted in increased hemoglobin and iron stores, along with significant improvements in sleep. No other symptoms were shown to improve and no side effects have been reported. Iron supplementation is safe and logical for children with low serum ferritin levels. Its low cost and ease of administration allocates the recommendation category - A (acceptable) for this subgroup. It is recommended to screen children with ASD for iron deficiency.

7. *Multivitamin/Mineral Supplements*

Poor nutritional status has been linked to severity of autism. Supplementation is indicated for sleep disturbances, gastrointestinal problems, hyperactivity, temper tantrums and self-injurious behaviors. An open label study and two other RCTs have demonstrated promising results. Vitamins/minerals supplementation helped improve symptoms of self-injurious behavior, aggression and tantrums. A non-randomized study compared conventional treatment to vitamin/mineral

supplements and revealed that supplementation lead to lowering of activity levels, decreased social withdrawal, reduced anger, better spontaneity, less irritability, markedly fewer adverse events, and less weight gain. These fall under the recommended category of drugs for those with a restricted or idiosyncratic diet and those with poor appetite, and is under the category A (acceptable) for all others.

8. *Carnosine/ L-Carnosine*

Carnosine is important for many normal body functions including the proper functioning and development of the muscles, heart, liver, kidneys, brain, and many other organs. Carnosine has been implicated in neuroprotection and frontal lobe function. Thus it has been indicated in the treatment of autism symptoms. A small recent study reported improved socialization and receptive vocabulary with carnosine. A double blinded RCT with 31 children with ASD, used the Gilliam Autism Rating Scale (total score and the Behavior, Socialization, and Communication subscales) and the Receptive One-Word Picture Vocabulary test and found significant difference between the l-carnosine and placebo groups. Hyperactivity and excitability were the main side effects of the drug. The deficiency of research and side effects pushes it to the bottom of the preference list.

9. *Melatonin*

Individuals with ASD are commonly reported to have associated sleep problems. Melatonin is a hormone that regulates sleep cycles. It is being used to help children with ASD having sleep abnormalities. Six studies reported improvements in daytime behavior as a result of night-time administration of Melatonin. It was associated with increased sleep duration and decrease in sleep onset latency, but night time awakenings were unchanged. Side effects of the drug are minimal to none. Small sample studies and the narrow indication limit its usage.

10. *Chelation*

It is a process for removing heavy metals from the blood and is used in treating ASDs associated with heavy metal toxicity. Heavy metals like cadmium, mercury and lead have been found in high levels in some children with autism. Thus elimination of these toxic metals with chelation forms the basis for expecting improvements in individuals with autism. Chelation involves a series of injections, of Dimercaptosuccinic acid (DMSA) or ethylenediaminetetraacetic acid (EDTA) which removes metals from the blood through subsequent urination. Two studies with DMSA illustrated high excretion of heavy metals and improvements in language, cognition, and sociability. Caution is expressed due to many side-effects. Chelation therapy is not FDA approved for lack of substantial evidence, theoretical basis and severe adverse effects like renal and hepatic toxicity, fatigue, and diarrhea. The less common side effects include abnormal complete blood count, mineral abnormalities, seizures, sulphur like smell, regression, GI symptoms and rash. It

is essential to evaluate individuals for heavy metal toxicity prior to administration. It is thus under the acceptable category of drugs only in those with heavy metal toxicity.

11. DMG

Dimethylglycine is also known as Vitamin B15, N-dimethylglycine, calcium pangamate or pangamic acid. DMG is also found in whole grains such as brown rice, pumpkin seeds, brewer's yeast and liver. DMG increases oxygen uptake in the blood and increases circulation, both of which increase nutrient absorption. DMG supplements are absorbed by the small intestine into the bloodstream and then converted to glycine by the liver. Glycine is one of the most basic amino acids, and is essential in the formation of methionine, choline, various neurotransmitters, numerous hormones, and DNA itself. It also boosts immune function and thus helps many people with autism who have immune system deficiencies. Dimethylglycine (DMG) is gaining popularity as a behavioral modification treatment for both children and adults with autism. DMG has also been shown to reduce seizures, which are also common in those with autism spectrum disorder. As a treatment for autism, DMG is supported by a great deal of anecdotal evidence from parents, health professionals and caregivers. There are mixed reports about its efficacy. Two small double blinded RCTs showed ineffective results. However there are reports of improvement in speech and behavior with no reported side effects.

Two studies on DMG in autism have shown that dimethylglycine supplements have no effect on behavioral symptoms. It has been argued that the researchers were using incorrect dosages or that the study was too small to be statistically significant. A more recent study involving 84 subjects was far more promising, and it is clear that more research needs to be done on the effects of DMG supplements on autism.

Advocates of DMG and many of those who have used DMG supplements to treat their children with autism, claim that DMG can improve eye contact and social interaction, increase and improve speech communication and increase frustration tolerance in those with autism. In severe cases, DMG may also decrease aggressive behavior, both towards self and others.

No serious side effects have been reported with DMG and it is recommended to take DMG tablets with food to avoid nausea. Some parents have reported hyperactivity in their children with autism as a side effect of taking DMG supplements. This can be avoided by supplementing the DMG with folic acid. This is said to provide an added beneficial effect. DMG supplements include both folic acid and vitamin B-12.

12. Cyproheptadine

This is tried as high levels of 5-HT have been reported in ASD. But due to some

risks involved it is not recommended. Sufficient research is not available to report the safety and efficacy of this as a treatment in autism.

13. *Secretin therapy*

Like most experimental treatments for autism, secretin therapy is also surrounded by controversy. Research has recently suggested that the characteristics of autistic spectrum disorders may be caused by the accumulation of particular undigested foods, such as those rich in casein and gluten. It is believed that people on the autism spectrum may have a deficiency of secretin in their digestive systems. In order to replace this deficiency, many scientists believe that doses of secretin might relieve these bowel symptoms and result in improved characteristics of autism. Studies have reported conflicting effects of secretin therapy.

To Conclude....

All parents want to see their children reach the highest levels of achievement. Even you as parents of children with autism would desire the same for your child. Once your child is diagnosed to lie on the autism spectrum, you must discuss all the available treatment options with your doctor. Gather sufficient information from various sources including other parents who could be part of a support group. One has to keep in mind that though autism may not be curable, there are multiple options to control the symptoms and improve the quality of life. Medicines reduce the distress caused by the symptoms, reduce their interference in daily activities and will help you manage your child better. As discussed above, there are prescription and non-prescription medications available that offer several advantages. Depending on the symptoms of

each child, a comprehensive individualized treatment program with a combination of drugs can be charted out. As there are no set guidelines for use of medications in autism, doctors may give recommendations after taking into consideration the risks and benefits of different medications that may suit your child. Once the medications are started, parents should closely watch for any side effects. You should be well informed about the possible side effects and ways of managing them. Request your doctor for information about precautions to be taken and any routine monitoring tests that may be required. There are many clinical studies which support the use of prescription and nonprescription medications, individually, but combination therapy may give added benefits. Inform your doctor about all the over the counter medications being used for your child so that any complications due to drug to drug interactions can be avoided. Remember, effectiveness of any therapy can be variable and cannot be predicted for a particular individual. Symptomatic improvements and effectiveness will be noticed if medications are consumed appropriately as prescribed by your doctor. Patiently give each drug sufficient time (approximately 6 months) to show beneficial results, provided there are no side effects. If you still find that they are not working, speak to your doctor about an alternative drug or dosage. Stay in constant touch with your doctor for monitoring the benefits and the side effects at regular intervals. Even when it comes to

the use of natural products, do not assume that they are always safe. Be sure to follow relevant directions provided on product labels and consult your pharmacist or physician or other healthcare professional before using them. Dosages are very important to be noted and followed meticulously. While putting your child on drugs for reducing the symptoms of autism, remember that going beyond is as bad as falling short. For example, having a dull and drowsy state on medicines is as undesired as hyperactive and irritable state. To summarize, medications should be used as a tool to improve the productivity of the child and quality of life of the family. In combination with various therapies it can serve as an effective modality in the overall management of autism.

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17. Occupational Therapy

What is Occupational Therapy?

The American Occupational Therapy Association (AOTA) defines occupational therapy as a "skilled treatment that helps individuals achieve independence in all facets of their lives. Occupational therapy assists people in developing the 'skills for the job of living' necessary for independent and satisfying lives". As parents and teachers, an independent and satisfying life for your children with autism, must surely be an important goal.

Occupational therapists traditionally focus on teaching activities of daily living (ADL) like eating, bathing, grooming, dressing etc. More specifically in autism, occupational therapists with expertise in Sensory/Motor Integration and Skill training, work on optimizing sensory processes, altering behaviors and training for developing gross and fine motor skills, communication, play and social skills. Children on the autism spectrum may benefit from occupational therapy, both at home and at school. Performance of age appropriate meaningful activities depend on the interaction between the people (includes individual's physical, cognitive or emotional ability), the environment (accessibility, structure, safety, and availability of supports to carry out activity) and the nature of the activity itself (complexity, repetitions, size and texture of objects etc.)

What are the Occupational therapy intervention methods and strategies?

The main areas of Occupational therapy intervention include:

- Sensory / Motor Integration
- Behavior Modification (this has been covered in detail in the section of psychological intervention)
- Skill Building (activities of daily living, handwriting, oro-motor skills, etc.)
- Prescribing, providing and training the use of Assistive technology and implementation of modifications at home (these have been covered in detail in the sections of assistive technology and modifications)

17.1 Sensory Motor Integration

What is Sensory/Motor Integration?

Before beginning with therapy techniques and strategies, it would be helpful for you if you understand about the normal process and importance of sensory processing and integration. By definition, Sensory integration (SI) is the neurological process that organizes sensation from one's own body and environment to perform an appropriate motor response. There are the commonly known 5 senses of the body, which are hearing, sight, touch, taste and smell.



Figure 17.1 (1) - The 5 Common Senses

The Five lesser-known senses which help our body work in harmony with the self and the environment are:

1. Proprioception and Kinesthesia - It's the sense that tells about the body's joints and muscle groups, how to react, move smoothly, and tells the body 'where your body is, in space'.
2. Vestibular or equilibrioception - It's the sense of balance involved with the inner ear that stabilizes visual fields when the head moves and maintains equilibrium.
3. Nociception- Perception of pain
4. Temporal Sense- sense of time
5. Thermoception- perception of temperature differences.

Sensory integration makes it possible to use our body effectively in response to inputs from the above senses in our environment. Children with autism are believed to have

difficulties receiving, assimilating, integrating and processing sensory information. As healthy individuals we unconsciously combine the above senses in order to use information from our environment. Children with autism have trouble learning to do this. Sensory integration therapy is a type of occupational therapy intervention that places a child in a room specifically designed to stimulate and challenge the senses.

Sensory integration therapy is driven by five key principles:

- The child must be able to successfully meet the challenges that are presented through playful activities (Just Right Challenge);
- The child adapts his/her behavior with new and useful strategies in response to the challenges presented (Adaptive Response);
- The child will want to participate because the activities are fun (Active Engagement); and
- The child's preferences are used to initiate therapeutic experiences within the session (Child Directed).
- The child has an inner drive that leads him to search for opportunities in the environment that leads to a sense of mastery over the environment (Inner drive)

The aim of sensory integration therapy is to improve the ability of the brain to process optimal sensory information from his body and surroundings and thereby reduce sensory issues. Sensory integration therapy is based on the assumption that the child is either over-stimulated or under-stimulated by the environment.

If the child is hypersensitive/ over-stimulated, your child may not like to get his hair or nails cut, he may dislike messy objects or food items and may be aversive to touch or hugs from people. This shows that your child has a low threshold for touch stimuli.

On the other hand, if the child is hypo-responsive/ under-stimulated, he/she may actively go, hug and touches even strangers, likes playing with fabrics or different textured materials, or mouthing of all objects. This demonstrates that he constantly seeks tactile inputs to meet his/her high threshold levels.

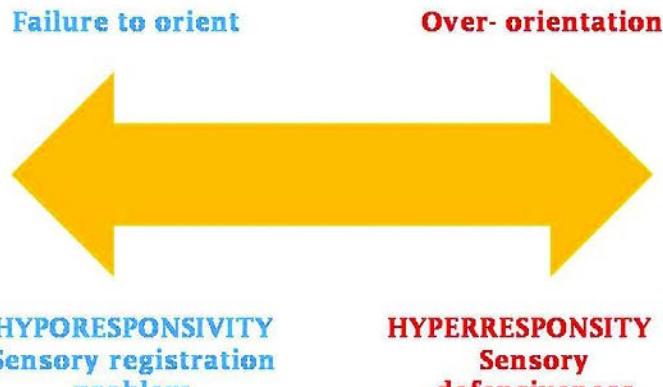


Figure 17. 1 (2) - Sensory processing spectrum

How does it benefit?

Problems with Sensory Integration may show themselves differently in each child. Activities are specific to a particular sensory system, or a combination based on the child's needs and tolerance. You may use these activities during the day and at home to enhance assimilation, processing and response to a variety of senses. They help in improving awareness, attention/ concentration, decreasing stereotypical (repetitive) behaviors, self-stimulatory behaviors, regulating state of arousal (hyper/hypo-activity), improving eye contact, communication skills, concept formations, planning and execution of motor tasks. These activities help the child's nervous system calm down and become more receptive to learning.

What are the common sensory integrative problems seen in children with autism and what activities can you do to resolve them?

A) The Tactile System

The tactile system includes nerves under the skin's surface that send information to the brain. This information includes light touch, pain, temperature, and pressure. These play an important role in perceiving the environment as well as protective reactions for survival.

Dysfunction in the tactile system can be seen in withdrawing when being touched, refusing to eat certain 'textured' foods and/or to wear certain types of clothing, disliking having one's hair or face washed, avoiding getting one's hands dirty (i.e., glue, sand, mud, finger-paint), and using one's finger tips rather than whole hands to manipulate objects. A dysfunctional tactile system may lead to a misperception of touch and/or pain (hyper or hyposensitive) and may lead to self-imposed isolation, general irritability, distractibility, and hyperactivity.

The child may not be able to discriminate objects by touch alone (i.e. find something in their pocket), may be injured without experiencing pain (high pain threshold), may appear clumsy (drops things), have poor body awareness (trip over things), have trouble planning a series of motor movements (climbing a ladder), be highly sensitive to light touch (tags on clothes, haircuts) or dislike sticky substances (like glue).

Tactile defensiveness is a condition in which an individual is extremely sensitive to light touch. Theoretically, when the tactile system is immature and working improperly, abnormal neural signals are sent to the brain which can interfere with other brain processes. This, in turn, causes the brain to be overly stimulated and may lead to excessive brain activity, which can neither be turned off nor organized. This type of over-stimulation in the brain can make it difficult for an individual to organize one's behavior and concentrate leading to a negative emotional response to touch sensations.

ACTIVITIES FOR TOUCH AND DEEP PRESSURE

Bear hugs, Back scratch	Jump on "crash pad", Log rolling on different surfaces like mat, floor, soft mattress etc.
Massage with/without lotion, oils	Use hand fidgets, play with a fidget basket with finger puppet, Koosh balls, squeeze toys, stretchy animals, glow tubes, etc and play with stuffed toys
Joint compressions	Make mud pies
Scrub with washcloth/scrubby	Arts & crafts with different materials
Wearing different fabrics	Use foamy soap/shaving cream
Explore various textures	Pet a dog, cat, or other animal
Sit in the sunshine/shade	Play with whipped cream
Mix cookie dough, cake batter	Roll up in a "burrito" blanket
Weighted blanket, vest, lap pad	"Sandwich" between pillows
Climb under sofa cushions	Play in sandbox
Use Play-doh, Sculpey, Silly Putty, clay, mashed potato, wheat dough with food Colors	Sensory bin with dry rice & beans, grains or other materials
Help with gardening	Vibrating objects like toothbrush, pens, balls, stuffed toys, etc.
Vibramat/Tender Vibes mattress	Ball pool activities
Finding hidden objects in a container of sand, beans, grains, rice, balls, foam wedge, buttons and beads, etc.	Water play with, water balloons and spray bottles
Finger painting with the use of textured materials like sand, rice, glitter glue, etc.	Use of warm towels/cloth with blow dryer after bath
Walking barefoot outdoors on a variety of surfaces like grass, concrete, sand, wet mud etc.	Drawing letters and shapes with finger on different textured surface such as velvet carpet. Erasing them with hands or feet.
Identifying shapes, letters, and numbers drawn on his or her arm, leg or back Vestibular and Proprioceptive Systems	

B) The Vestibular System

It refers to structures within the inner ear (the semi-circular canals) that detect movement and changes in the position of the head. Dysfunction within this system may manifest itself in two different ways. Some children may be hypersensitive to vestibular stimulation and have fearful reactions to ordinary movement activities (e.g., swings, slides, ramps, inclines). They may also have trouble learning to climb or descend stairs or hills; and they may be apprehensive of walking or crawling on uneven or unstable surfaces and appear clumsy. On the other extreme, the child may actively seek very intense sensory experiences such as excessive body whirling, jumping, and/or spinning. This type of child demonstrates signs of a hyposensitive vestibular system; i.e., they are trying continuously to stimulate their vestibular systems. This may lead to loss of balance if the head is tilted or trouble in recovering from movement (i.e. car sickness, dizziness after swinging). They may also not get dizzy at all and may crave excessive movement (rocking, swinging).

C) The Proprioceptive System

This refers to components of muscles, joints, and tendons that provide a person with a subconscious awareness of body position. When proprioception is functioning efficiently, an individual's body position is automatically adjusted in different situations. For example, the proprioceptive system is responsible for providing the body with the necessary signals to allow us to sit properly in a chair. Some common signs of proprioceptive dysfunction are clumsiness, a tendency to fall, a lack of awareness of body position in space, odd body posturing, minimal crawling when young, eating in a sloppy manner, and resistance to new motor movement activities. The child may use too much or too little force when pushing, pulling, lifting or holding, have trouble with small fine motor skills (managing coins, writing, zippers), may appear stiff or have an unusual gait. They may also have trouble knowing where their body ends and objects begin (running a hand over a wall to determine body placement, infants may confuse mother's body as part of their own).

ACTIVITIES FOR THE VESTIBULAR AND PROPRIOCEPTIVE SYSTEMS

Rocking (in your arms, rocking horse, or rocking chair)	Floor push-ups, Wall push-ups, Sit ups
Crawling on hands and knees	Use swings of different kinds (platform, hammock, tyre, bolster, trapeze, rotator etc.)
Commando crawling with full body	Playground slides
Walk, Run, Jump	Use monkey bars, Climb stairs, climb an inclined ramp, Climb ladders
March, Dance, Bunny hop	Jump on mini-trampoline

Wheelbarrow walk, Animal walks, Jumping jacks	Use Sit n' Spin, Dizzy Disc Jr., or other spinning toys
Therapy ball activities like bouncing on the ball, deep pressure under a ball	Hoop-It balls
Inflatable seat cushions	Ride a tricycle/bicycle
Ride a scooter/skateboard	Amusement park rides
Swimming	Push a grocery cart or stroller
Brain Gym and yoga exercises	Roll down a hill
Hokey Pokey	Play catch
Balloon tennis	Play hopscotch
Cartwheels and somersaults Jumper	Ice skating/sledding/skiing/Bungee
Play in sand box with damp, heavy sand	Use cardboard boxes with blankets and pillows to make forts
Rearrange bedroom furniture	Open and Close doors for people

D) The Auditory system

Difficulty processing auditory (sound) inputs can lead to problems in understanding language (discriminating between similar words, organizing spoken words to determine meaning), selecting what to listen to (i.e. if your name is called) and filtering out background noise (i.e. the air conditioner hum), experiencing a delay in one ear but not both (makes for garbled input), hearing sounds as too loud or too soft (may hear sounds others can't), closing their ears in apprehension or fear of any loud or disturbing sounds and poor attention or concentration.

ACTIVITIES TO IMPROVE LISTENING AND THE AUDITORY PROCESSING INCLUDE

Listen to favorite music	Therapeutic Listening programs
Identify appropriate music (calming or arousing)	White noise machine or CD
Bang on pots and pans	Observe silence
Play musical instruments (drums, piano etc.)	Identify, match and label sounds
Listen to sounds of nature outdoors	Use earplugs or sound-cancelling headphones
Singing, Humming, Whispering	Explore the stereo volume control knob
Blow whistles, flutes etc.	Create a "Safe space" with quiet and low light



Figure 17.1 (3): Playing in the Ball pool



Figure 17.1 (4): Put balls inside their shirt and have them remove it



Figure 17.1 (5): Floor painting with one's feet



Figure 17.1 (6): Clay activities



Figure 17.1 (7): Wrap with different textures



Figure 17.1 (8): Deep Pressure



Figure 17.1 (9): Pulling a theraband



Figure 17.1 (10): Weight bearing activity

E) Vision and visual-perceptual skills

Children with autism can see an object as they have a completely normal vision, which is proved by normal ophthalmology/eye check up reports. The problem lies in the processing of the visual information. For example, they can see an apple but cannot make out its characteristic features like it is red in color, its shape, and thus cannot identify it. As a result they do not exhibit any interest in the object and are unable to sustain their vision on it. This inability to sustain vision on relevant inputs coupled with deficits in perceiving can lead to problems in eye-contact, eye-hand co-ordination and tracking of objects or people. Problems may also be seen in depth perception (may miss obstacles or misjudge distances), directionality to determine where things are (left/right, up/down, etc.) and form constancy (the ability to recognize the objects in spite of variation in environment, position and size). Visual memory (retaining an accurate picture of an environment to remember information) and sequential memory (what comes first) may also be compromised. The child may over-focus on details or unimportant inputs and miss out on the relevant details (looking at a car's design without realizing the danger of being hit by it). Hence, the brain must be trained to assimilate, integrate and appropriately process the information received through the eyes.

Visual processing is important for appropriate perception and learning. Many children with autism do not see things around them as we do. Images of objects are often fragmented down to the minute parts and components. Some may have difficulty focusing visually on the images or objects presented. Processing and making sense of such distorted images and consequent learning is thus affected. Some of the common signs of dysfunction of this domain includes finger flicking near eyes, tilting one's head while looking at things, aversion for escalators, dislike for fluorescent lights, cannot tolerate flickering light, struggles to play catch with a ball and examination of the eye shows normal results.

ACTIVITIES TO IMPROVE VISION AND PERCEPTION

Look at mobiles, lava lamps, bubble lamps, disco globes, colored rotating discs, colored light bulbs	Avoid fluorescent bulbs (visual flicker, noise, and mercury content in compact fluorescents)
"Safe space" with minimal visuals	Toys in opaque containers
Respect color preference in clothing, objects, and interior decorating	Avoid complicated prints and patterns On clothing, walls, and floors
Leave out 5-10 toys at a time to avoid visual overload	Look at photos, look at picture books
Look at nature - fish tanks, farm, zoo, ocean	Watch cartoons and movies
Use high-quality sunglasses outdoors, tinted lenses indoors if sensitive to glare	Games and activities that develop visual skills like mazes, dot-to-dots, I-Spy, drawing, flashlight tag, etc

Play hide and seek of small object in a room	Activities like spot the differences, find the odd one out, follow the light, etc.
Use of incandescent lamp by the desk	Blocking or avoiding fluorescent lighting
Use of laptop or tablets	Grey, tan or pastel paper to reduce the contrast
Use of Irlen lenses or pale colored glasses	Balancing games on a vestibular ball
Use of prism glasses prescribed by a developmental optometrist	

F) Smell/ Taste/ Oral Systems

Children may be a very 'picky' about the foods they eat, which can interfere with proper nutrition. They may gag or vomit easily. They may seek oral sensations such as hard or crunchy foods like chips, may constantly mouth or smell their hands or any object. Some children may go around smelling strangers too. This behavior is generally, an extension of the child's impaired sensory functions, i.e. improperly developed reaction to various sensations. Hence, as seen in the other senses, the child has to be slowly introduced to a variety of smells and tastes and taught their relevance.

ACTIVITIES TO RESOLVE ISSUES RELATED TO THESE SYSTEMS

Use of essential oils and scented candles	Smell flowers, sniff spices and herbs
Explore child's personal preferences and discover invigorating (typically lemon and peppermint) versus calming (typically vanilla, rose and sweet orange)	Explore tastes: sweet, salty, sour, spicy, bitter
Blindfold smelling game	Eat frozen/cool/warm foods
Explore textures: crunchy, creamy, chewy, Lumpy	Explore textures: crunchy, creamy, chewy, lumpy
Blow soap bubbles, blow a balloon	Suck thick liquid through straw
Use of age appropriate "chewey" tubes	

G) Motor planning and execution (praxis)

It is very important for children with ASD to develop good praxis because they are required to manage everyday situations that are constantly changing. Even routine activities, such as riding the bus to school requires the child adapt to new stimuli and situations (different children, different driving conditions, different

seat mates, different seat belts). Praxis problems difficulty in planning and executing motor tasks can make learning skills like dressing, toileting, sequencing, packing a bag for school etc., very difficult. Help your child to develop praxis by providing him or her with varied sensory experiences. Once a desired level of organization is achieved, introduce the activities that challenge the child.



Figure 17.1 (11) Crossing Obstacles

ACTIVITIES TO IMPROVE PRAXIS

Ride tricycles and bicycles	Participate in imaginative play (house-keeping, fireman, doctor, post office)
Create and complete an obstacle course with variety of obstacles and goals	Play "mirror image" and imitation games like "Simon Says"
Play "red light/green light" - child run on green light and stops on red light	Action songs like "This is the way I brush my teeth..."
Play "follow-the-leader" "In and Out"	Quick response games, like "In and Out"
Play hand-games with songs, claps, snaps etc.	Playing hop-scotch
Use of puzzles, mazes, legos, block designs, etc. to understand relations between objects, directions, manipulations etc.	

How to deliver effective Sensory Integration therapy?

To be effective, sensory activities must be done every day just like medications need to be taken every day in order for them to be effective. Try doing some discrete learning tasks while the child receives soothing pressure. Your child may learn best when he lies across a beanbag chair with another bag placed on top of him (sandwich style). The pressure may calm his nervous system and prepare him for learning. Try slow swinging for 10 to 12 times a minute, during the lesson. Swinging helps stimulate language, encourage eye contact, and improve concentration. Teaching concepts like shapes, colors, numbers, sorting, counting, etc. are best learnt while on a slow swing.

To help a fidgety, restless child sit still and attend to his lesson, try a weighted vest. The vest is most effective if the child wears it for 20 minutes and then takes it off for 20 minutes. This prevents habituation. In between study times give a break to your child when he can play with 'fidgets', or can jump 50 times on the trampoline or gym ball. This will satisfy his urge to move or spend his energy and help him focus better on the learning task. You may also ask your child to do a series of physical activities like jumping, running up and down stairs, doing sit ups

Conversely, in a low energy, hypo-aroused child with a slow sensory system, learning can occur while doing a drill or while the child jumps on a trampoline, or by using a vibrating chair pad. Creating a visual room can be beneficial. Put in different colored lights, mirrors, colorful rotating discs, radium stickers of planets or stars, disco globes etc. Use them in a variety of ways to improve attention, concentration and eye contact.

Pick the best activity for your child by:

- Choosing activities wherein your child can lead direct or guide the play. This provides the opportunity to initiate a play activity.
- Finding out what works best and spread it across to other avenues. Maintain consistency between home and school to ensure learning, maximize results and confidence.
- Choosing age-appropriate activities, while keeping in mind that there could be a gap between his/her chronological age and developmental age. The best activities accommodate the child's abilities and sensory needs and tolerance levels.
- Involving other family members to participate.
- Designing them in such a way that they do not require an elaborate budget, space, or schedule.

Points to ponder...

Some of the most severe children with autism function like a TV with bad reception. Visual and auditory perception may fade in and out depending on the strength of the signal. In the most severe cases, visual and auditory information is scrambled, rendering the child unable to decipher what he sees or hears at any given moment. Recent brain

scan studies show that the brain circuits that perceive complex sounds are abnormal. Sensory integration activities may help unscramble the child's perception and enable information to get through - a prerequisite for any type of learning.

Emotional regulation is a problem in many children with ASD. They may have intense emotional reactions to sensory stimuli and have difficulty calming down (i.e. the fire bell can result in behavioral breakdowns through the rest of the day), and the rate of recovery from reactions to stimuli may be slow (may need extended or regularly scheduled break times to maintain control). Sensory issues can affect mood (anxiety and depression), social skills and relating to others, behavioral breakdowns, and learning. Management of these has been explained in the following chapter. All the above activities must be chosen carefully. Do not bombard the child with too many activities at a time and force him/her to participate. SI activities should be like free play and must be enjoyable. You could use cuing, imitation, shaping, chaining and many other behavior techniques while providing these activities to your child. These have been explained in the following chapter.

A word of caution....

While sensory challenges often lessen over time, and especially as a result of SI treatment, we must acknowledge the detrimental effects that sensory impairments have on the ability of children with ASD to benefit from any treatment and plan accordingly. Sensory integration should be an important part of any treatment program for a person with ASD.

Too much of anything can be harmful. Though sensory activities are beneficial you must be able to read the warning signs of discomfort or overload. These can trigger a meltdown. If any of the following are observed, stop the activity at once. Take the child out of the situation. Consult your occupational therapist for advice on the prescription of activities. The following are the signs of discomfort or overload:

- Imbalance
- Disorientation
- Skin flushes
- Uncontrolled crying, screaming
- Stomach distress, vomiting, nausea, cramps, etc.
- Profuse sweating
- Increasing heart rate, sudden drop in pulse
- Child verbalizes "STOP!"
- Excessive agitation or anger
- Sudden increase in echolalic, irrelevant or repetitive speech
- Increased stimming behaviors
- Increased self-injurious behaviors
- Child lashes out, hits or bites others

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- 4) Iwanaga R, Honda S, Nakane H, Tanaka K, Toeda H, Tanaka G. Pilot study: efficacy of sensory integration therapy for Japanese children with high-functioning autism spectrum disorder. *Occup Ther Int.* 2014 Mar;21(1):4-11.
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- 6) Roley SS, Mailloux Z, Parham LD, Schaaf RC, Lane CJ, Cermak S. Sensory integration and praxis patterns in children with autism. *Am J Occup Ther.* 2015 Jan Feb;69(1):6901220010p1-8.
- 7) Lauren M. Little; John Sideris; Karla Ausderau; Grace T. Baranek. Activity Participation Among Children With Autism Spectrum Disorder. *American Journal of Occupational Therapy,* March / April 2014, Vol. 68, 177-185.

17.2 Training For Activities Of Daily Living

One of the earliest life skills that you would teach your child is to perform basic activities of daily living like eating food, washing his/her hands and face, brushing teeth, taking a bath or shower, combing one's hair etc. These are developmental tasks that must be taught one after the other, according to the child's age. While the average child can learn all of these skills by the time that they are five or six, children with autism often struggle with these tasks. An occupational therapist would work on training your child for all the ADL tasks. The information below may help you train your child at home. These simple and practical methods will help children on the autism spectrum to develop vital self-care skills. The common techniques used for training these children include:

- Demonstration and Imitation
- Chaining and use of reinforcements
- Picture cards, visual aids (Show them pictures of steps in the activity)
- Prompts, verbal cues, manual hand-over-hand guidance
- Audio- visual aids (cartoon video, nursery rimes like- This is the way I brush my teeth
- Modifying the tasks (to a way in which they may be performed), equipments or the environment
- Helping them cope with the sensory issues (de-sensitization)

A combination of the above techniques can be used to teach all of the following skills. You may try and identify what works best with your child.

A) Eating

Generally, the first activity that a child learns is to eat. Children with autism may even put inedible items into their mouth. So teaching them to eat by themselves begins with showing them pictures of eatable and non-eatable items to help them identify and differentiate the two.

- It can be done through sorting activities. Place two baskets and ask the child to separate eatables from the non-eatables. You may initially demonstrate and explain to the child.
- If your child is non-verbal use picture cards to show him the different steps of eating or demonstration.
- A step wise imitation by asking the child to copy each of your actions may also be useful.
- Easily understood, simple and short verbal cues could be used. For example, mix the rice, pick up with your fingers, take it to your mouth, etc.

- If your child loves music, you can teach him / her with the help of videos of nursery rhymes that include such activity.
- Begin with use of a spoon to eat. Once the child learns this you may teach the use of hands to eat, as this is a much more complex skill.
- Begin with solid, dry foods like wafers, biscuits or cheerios and then shift to messier foods like curry, rice etc.
- It is best to teach the child in a natural setup. Ensure that he eats along with the other family members so that through imitation he learns how to eat by himself at outside social settings. Teach the skill as part of the daily routine.
- The techniques mentioned above for eating are also applicable for drinking. Often poor eye-hand co-ordination hinders drinking from a glass or bottle. You could start with a sipper before shifting to a cup or glass.

B) Brushing teeth

Brushing one's teeth is another personal hygiene task that can be difficult for a child with autism considering the sensory issues. This time the aversion has to do with a foreign object entering the mouth, the texture of the brush and the taste of the toothpaste. You can start with an electric toothbrush of some attractive color or with your child's favorite cartoon on it. The vibration from the electric toothbrush and the familiar cartoon will make this task more enjoyable. To teach this activity break the task into the following steps for the use of picture cards, demonstration or imitation.

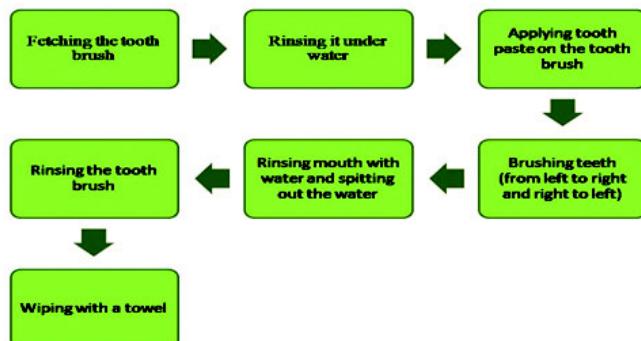


Figure 17.2 (1) - Brushing Teeth

Brushing Teeth



Figure 17.2 (2) - Brushing Teeth

C) Washing face and hand

The best way to teach this skill is through imitation and showing step-wise pictures of the activity. Some children do not like washing their hands or face with soap as the sensation bothers them. Some techniques to resolve these are:

- Using hand sanitizer instead of soap to clean one's hands
- Using soap that lathers less
- Using a wet tissue wipe instead of a face wash

Washing Face and Hand



Figure 17.2 (3) : Washing Face

D) Combing Hair

If your child is resistant to combing his hair, it could just be due to the brush or comb that you are using. You can overcome this problem by letting them try a variety of brushes, to find the one that they like the feel of or the look of. To teach the motion you could start by having them use their hand to smoothen their hair in a brushing motion. Next you could demonstrate how to comb by brushing your hair in front of your child. Finally, you must have them try brushing their own hair. Doing this in front of a mirror makes it more fun and is easy to learn.

E) Bathing

Before taking your child for a bath, please ensure that your child also wants to have a bath. Mentally prepare them because while some children enjoy the water, some don't. Sometimes they are not comfortable with the soap's texture or smell. A minimum of two or three options should be made available, so that the children is motivated and enjoys bathing. Use of a loofah can also be stressful to the child's senses. You may avoid it or select materials that he/ she is less aversive to.

Colorful pictures on the wall tiles indicating the steps for bathing can be helpful. As parents you could bathe with the child and ask him/ her to imitate you while you guide them through verbal cues. Ensure minimum distraction in bathroom. For example install taps of faucets which make less noise when operated. The sound of running water can bother them. Check for the optimal water temperature that best suits your child. Use more colorful pictures or stickers to teach them the difference between hot

and cold. For example, use the picture of boiling water for hot water and picture of ice for cold water.

Whenever you are teaching these activities to your child, be calm and patient. Do not hurry your child. While giving verbal commands, wait for your child's response before giving the next command. Teaching these activities may be time consuming, but with regular practice they will be able to learn the skills.

Once your child has learned bathing, then next step would be washing their hair. Washing hair is a big challenge. The difficulty may have to do with several factors including water temperature, the feel of water on their head, soap getting in their eyes and the texture or smell of the shampoo. A good way to overcome these problems is to adjust various aspects of the hair washing routine until you find the perfect combination that makes your child comfortable. Again, with practice your child will be independent for washing his/ her hair.

F) Dressing

Children with autism insist on wearing the same outfit everyday like a uniform. Many children with autism protest when having to dress in the morning for school or for family outings. Before teaching your kid to dress or undress, it is important to select appropriate clothing for your child.

- While you are purchasing clothes for your child, you should ensure that you are buying cloths of his/her choice.
- Keep in mind the kind of textures, colors and fitting the child prefers and the ones they dislike. Choosing items made from soft fabrics will minimize problems related to sensory issues. Clothing should also be loose fitting and comfortable.
- Look for the inner tags which may irritate the child. Pick clothes with lesser tags or tags that are completely sewed to the cloth.
- Pick clothes that have a clear demarcation between the front and back side. It is a good idea to select items that have a picture on the front, as this will give them a visual prompt as to which is the right way around. For example, a T-shirt with a bold logo on the front, underwear featuring popular cartoons or a dress with a zip at the back.
- It is a good idea to choose clothes with as few fastenings as possible, such as T-shirts and trousers with an elastic waist.
- Selecting items with Velcro fastenings or large buttons and zips will help the child to develop the fine motor skills needed in order to master the art of fastening and unfastening clothes. As time progresses, items with smaller buttons can be used.

Getting Undressed

Autistic children often lack basic self-care skills due to poor motor coordination and praxis issues (motor planning and organizing difficulties). Getting dressed can be a hard skill to master. There are several issues which make the daily routine of dressing

and undressing difficult for a child with autism. They may lack the fine motor skills needed to fasten buttons or zips, or the cognitive skills to remember in which order to put the clothes on. Another issue with autistic children and clothing is that the child may have sensory issues, with an enhanced sensitivity to clothes that feel rough to the touch, or feel too tight or restrictive.

It can be a good idea to get the child to get used to undressing before moving on to dressing skills, as it is a lot easier to take clothes off than to put them on. The first step in learning how to get dressed is actually learning how to get undressed. Fortunately, this is a skill that most autistic children learn by themselves. While getting undressed, ensure that the child goes to a private area like a bedroom or a bathroom. Teach the child to lock the door behind him and check the window drapes before undressing.

Getting dressed

A good strategy when teaching an autistic child how to get dressed is to allow plenty of time. It is not a good idea to try and master these skills when there is a limited time, for example when rushing to get ready for school in the morning. It would be more appropriate to practice in the evening before bed, when the child can begin by attempting to put on pajamas, which are relatively easy to put on and have no fastenings to worry about.

Dressing includes putting on several items of clothing in the right sequence. A visual timeline can also be very helpful to the autistic child, with clear pictures showing the correct order for putting on clothing. The clothing could be laid out on the floor in the sequence that it is put on.

Getting Dressed



Figure 17.2 (4) - Getting dressed

Putting on underwear: Changing their underwear is the next step. This step is pretty easy as they most likely already know how to take off their underwear, diaper or pull-ups.

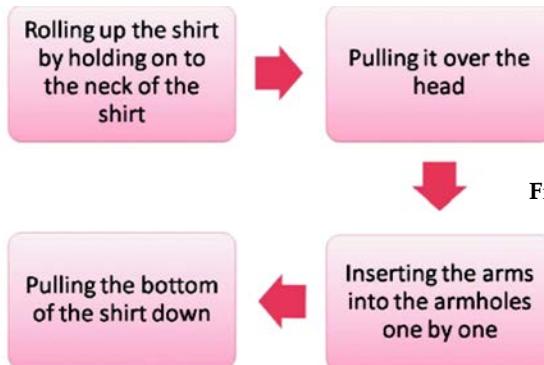


Figure 17.2 (5) - Getting dressed

To show them how to put on their underwear, use demonstration. You could do it first and then ask your child to imitate. Use verbal cues and hand-on-hand guidance. Use forward chaining techniques i.e., initiate the task by putting the child's feet into the underwear and pulling it half way up his/ her legs. Then ask your child to complete it by pulling it up to his waist. Doing this in front of the mirror makes it easier to learn.

Shirts and Pants: It may be difficult to learn dressing on oneself. Use a doll of a boy or a girl, as appropriate for your kid. He/ she may first learn the steps by dressing the doll and the practice on oneself.

A sticker chart can be a useful aid. A reward can be given every time the child masters a new skill

To teach how to put on upper body clothing, start with a T-shirt that is easy to pull over. Demonstrate the following steps to the child:

Next you could train for wearing pants. Show them how to put his/ her legs into their pants and pull them up. Always start with loose pants which will be easy for the child to put on. Once he learns this, you could gradually start teaching to zip and button.

If there are any garments in the home with large buttons, the parent can sit with the child during a quiet time and practice fastening and unfastening the buttons and make it into a game. An adult's cardigan would be ideal for this activity.

Shoes and Socks: If your child has fine motor difficulties, putting on socks and shoes will be difficult to learn. To make putting socks on easier to do, you can pull the socks on over your arm to stretch it out a bit before they try to pull it on to their foot. To teach the steps for putting on shoes and socks you can use social stories, you can demonstrate the steps, you can narrate the steps and you can assist your child in completing each step. Use a lacing board where the child can practice the skill. Again, the use of forward chaining techniques may be helpful. If lacing is just too difficult to learn, you may switch to shoes with Velcro or slip-ons.

Reference :

- 1) http://education.qld.gov.au/studentservices/inclusive/prep/docs/prep_factsheets08_6.pdf.

17.3 Toilet Training

Independent toileting is an important developmental milestone under ADL (activities of daily living) skills. The primary goal of training is to increase independence, social acceptance and reduce the load on family members. Toilet training can be stressful for you as a parent and traumatic for the child. Teaching your child to use the toilet in the right way and at the right time can be a difficult task, whether they have autism or not. But if your child has autism, the process of developing a toilet routine can be much more challenging.

When (at what age) is it appropriate to start with toilet training?

Toileting is a complex task which your child should learn before he/ she enters school at the age of five years. The following skills must be mastered before you can begin with toilet training:

- Dressing and undressing
- Manipulation of fine papers,
- Awareness of bowel and bladder sensation,
- Gross co-ordination and body awareness
- Comfort and tolerance to multiple sensory inputs like noise, textures, temperatures etc.

Achieving bladder and bowel control contributes significantly to a child's self esteem. Ensure parental support and reinforcements during the initial sessions of training.

What are the hurdles you could face while training your child for toilet use?

Children with autism have difficulty in comprehending your commands and the logic behind the task. Your child may struggle to understand what is expected of him/ her with regards to toileting. They may fail to understand why they need to eliminate in the toilet and not in their diaper.

Furthermore, their attachment to routines and resistance to change may make the transition from diapers to the toilet difficult. Having used diapers daily for 2 to 4 years, they may be attached to the sensation. They may not like the stimulating environment of the bathroom with its bright lights, colorful tiles, echoes, and sounds of running and flushing water. Aversion to changes in temperature, repeated dressing and undressing and washing/ cleaning may be a problem.

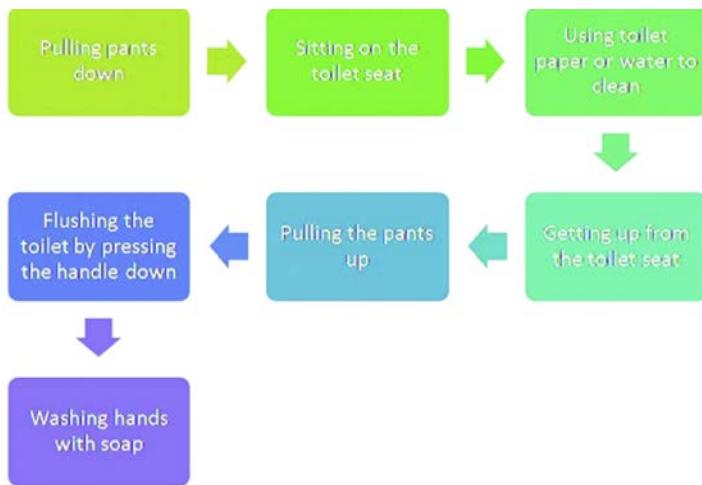
They may not know how to read bodily cues, and therefore are not aware of the urge to use the toilet. These children may not understand the sensation of being soiled (dirty). All of these above indicate the need for adaptation of classic toilet training methods to suit the special needs of children with autism.

What are some of the successful strategies you could use in children with autism for toilet training?

Toilet training follows a developmental pattern. It includes progression from daytime continence (control) to night-time continence, to reliability in toileting in familiar environments and then to generalizing those skills to other unfamiliar environments. The following strategies may help with toilet training.

Behavioral strategies:

Breaking down into a step-by-step manner with rewards and positive reinforcement can help with toilet training. The complex task of going to the toilet should be taught in a series of small steps. Perform each step yourself and then ask your child to do the same. The steps are as follows:



17.3(1) Steps for Toilet training

Teach one step at a time. As your child learns each step you could reward him for the same. This will encourage him to pay attention during training and learn faster. You may use forward and backward chaining techniques as explained in the next chapter on Psychological intervention. You may initiate the task by taking your child to the toilet and unbuttoning his pants. The steps that follow can then be performed by him/her with some verbal cues or hand-on-hand guidance from you. Ensure that the last step of flushing and washing hands is completed by the child himself. This will provide with increased confidence and the feeling of having completed the task. Similarly the reverse can be practiced later, i.e. the child initiates the task and you may perform just the last few steps of it. This will help improve initiation. Lastly, complete sequences can be practiced.

Visual aids or supports and imitation:

Children with ASD are often visual learners. So you can support your child's learning by providing visual cues and prompts.

- Visual schedules depicting the steps of toileting can help to reinforce the routine of using the toilet, and provide reminders for taking regular toilet breaks.
- The schedule can be stuck on a wall close to the toilet or potty.
- Go over the schedule with your child 2-3 times a day.
- All those who assist your child with toileting need to know and follow the routine. This way, training will be consistent.
- You can use alarms every two hours to remind them to empty their bladder.
- Use demonstrations and imitations of the above mentioned steps.
- Make sure that routine of toileting is followed consistently.

De-sensitization or modifications to accommodate sensory issues:

If your child is sensitive to the sensory aspects of going to the toilet, there are few techniques to control the sensory experiences of toileting. For example:

Get your child familiar with sitting on the toilet seat by practicing for a few minutes every day

If the cold toilet floor bothers the child, help him/ her put on socks. Try to match the temperature in the toilet to the rest of the house

Keep the toilet floor as dry as possible

Use a foot stool if your child needs support while sitting on the toilet

Use a training seat if your child is scared of the big hole over the water

Hand showers or jet sprays should be moderated such that the water force is not too high (forceful, pressured flow of water can be threatening)

Prepare the child for a noisy sound before flushing and explain why the flush is necessary (you may have silent flushes installed)

Try avoiding soaps that produce too much froth or lather as they may dislike it

Pre-adjust the water temperature to the room-temperature

Keep the lighting simple and not too bright

Keep the toilet as clutter-free as possible

Sometimes these children suffer from constipation, so eating high fiber foods and drinking lots of fluids will help achieve regular elimination.

Because of the process of toilet training has many steps, it is important for you and your child that success be defined in the accomplishment of each small and separate step. It takes long time to make them independent in toileting, so you should have patience. If toilet training becomes a battle with no signs of progress you should take a break, for now. You could consider training again in about three months, when your child is better prepared.

References:

- 1) Raising Children Network : Toilet Training for children with autism spectrum disorder http://raisingchildren.net.au/articles/autism_spectrum_disorder_toilet_training.html
- 2) The National Autistic Society: Toilet Training <http://www.autism.org.uk/living-with-autism/understanding-behaviour/toilet-training.aspx>

17.4 Skill Development

How can you work on skill building?

An occupational therapist helps train your child in daily living skills necessary to function independently at home and in school. With a mix of sensory issues, praxis problems, communication deficits children with autism find it challenging to learn these skills. Below are outlined training methods and strategies for building hand-writing and oromotor skills in children on the ASD spectrum.

A) Training for Hand-writing skills :

Hill (2006) describes learning to write or to represent language in written symbols as involving learning to use a writing tool, to hold it properly and to create letters, words and sentences to convey meaning to others. These have been observed to be poor in individuals with autism. Handwriting skills are crucial for success in school, communication, and building a children's self-esteem. It is a highly complex skill that develops slowly after birth through 7 years of age. Many individuals with ASD do have some level of fine and gross motor difficulty along with sensory difficulties. This often manifests itself as poor handwriting.

While training for hand-writing, ensure the following points.

- Teaching table or desk should be clear and clutter-free
- The room should not be crowded and should be distraction free
- There should not be much sound
- Proper height of table and chair
- Good Posture

Building the foundation for hand-writing skills :

Before training for hand-writing skills you must work on the child's proximal strength and stability (trunk, shoulders and elbows), posture, hand functions, attention span, eye-hand co-ordination and motor planning.

ACTIVITIES TO IMPROVE POSTURE AND PROXIMAL STABILITY

Weight bearing activities such as wheelbarrow walks, bear walks, crab walking or crawling like different animals helps improve shoulder stability which is important for control of the arm	Side sitting and weight bearing on one arm while building blocks, dumping sand in a sand box, or playing with a container of water, toys helps strengthen the forearm
Climbing on playground equipment like ladders, slides, etc.	Pull, push and punching activities

Supine flexion and prone extension positions on floor mats, swings, etc.	Throwing all different sizes and weights of beanbags, small balls, koosh ball or beanbags at targets
Bat and ball games	Wringing out sponges or washcloths
Hitting balloons	Turning door knobs/ door handles
Hammering activities (For example, 'Don't Break the Ice' is a game which involves using a hammer to break the ice blocks)	

ACTIVITIES TO IMPROVE HAND FUNCTION

Pegs and pegboards	Pop it beads
Use tweezers to pick up small objects like beans or cotton balls	Water or Air squirt
Using Stamps and stamp blocks	Use an eyedropper to make pictures by mixing food coloring with water and dripping it onto paper towels or coffee filters.
Popping bubble wrap paper	Games played with tools such as Bed Bugs, Crocodile Dentist, Thin Ice, Trouble
Etch-a-sketch	Playing with winding toys, tops etc.
Construction sets such as tinker toys lego's, Lincoln logs or unifix cubes	Play-doh activities. For example, roll clay into small balls with the fingers; make different clay models, pinching clay.
Roll balls of tissue paper between thumb and fingers to make pictures	Finger painting
Squeezing small balls	Playing with sand and water
Crumpling a sheet of newspaper or scrap paper	Using the "tripod" fingers (thumb, index and middle fingers) for games like Dominoes, Chess, Snake and Ladders, etc.
Finger puppet play	Collecting and sorting of loose coins
Painting using vegetables like cut potatoes, lady's finger, etc.	



Figure 17.4(1): Thick pencil



Figure 17.4(2): Weighted pencils



Figure 17.4(3): Slanted board



Figure 17.4(4): Pencil with wrist band

ACTIVITIES TO IMPROVE EYE-HAND CO-ORDINATION AND ATTENTION SPAN

Joining dots, solving mazes etc.	Bead stringing, garland or bracelet making activities
Paper cutting on lines or zigzag patterns	Doing craft activities like, Origami
Lacing boards	Using stencils
Playing musical toys like a piano	Playing card games
Folding paper into simple shapes or folding napkins for dinner	

Some additional techniques to facilitate hand-writing skills :

- Special assistive devices can be used to aid in better hand-writing skills. Some of these include:
 - Thick pencils
 - Pencils with grippers
 - Vibratory pencils
 - Weighted pencils
 - Slanted board
 - Pencils which connects to the child's wrist through an elastic band
- During the initial stages, instead of getting your child to write complete alphabets, start with joining dots using a dark colored pen or pencil. This will improve the child's eye hand co-ordination and attention. At the end of the line, draw a vertical small line to indicate that no writing should be done beyond this point or write the word "STOP".
- When the child starts writing, the best way is to begin with thick crayons instead of a pencil. Thick crayons are easy to hold and at the beginning children tend to apply more pressure while writing. Therefore, crayons would prove to be easier as against to pencils.
- Once your child gets comfortable writing with crayon, gradually go for a pencil. You have to ensure that the child is comfortable with the type of pencil he is using, before starting the training session with the child.
- Avoid too many instructions at a time, because these children find it difficult to grasp and are slow in information processing.
- The use of a slanted board is highly efficient for kids who press hard on the paper with the pencil to the point of making holes in the paper. The slanted (slightly lifted) board forces the child to reduce the pressure on the paper.

- When you are working with child at home or in school there should not be much distraction in the room like, too many people coming in the room, colorful pictures on wall, or any game or colorful objects on the table or any type of sound which could hurt the child's ear.
- When the child's performance of writing gets better, reward him with something of interest like any food item, a game to play, a cartoon to watch, etc. so that will increase child interest and motivation towards writing.
- Practice every day at a fixed time to set it into his/ her routine.
- In school the teacher should adjust the classroom handwriting requirements according to child interest and need. The writing requirements should be eased off the child. Writing work can be broken down into smaller sessions.
- Alternative positions can be tried to improve proximal stability and hand functions. For example, lying on the floor on the stomach, kneeling or working at the chalkboard, easel or paper taped on a wall.

These children with autism are special and they have their own way of learning. So be patient, provide practice sessions regularly. Gradually your child will be able to develop hand writing skills.

B) Oro-Motor skills training :

Some children with autism may have oro-motor problems. These include drooling, inability to swallow saliva, inability to perform different tongue and lip movements for activities like chewing, licking, sucking, blowing and speaking. Oro-motor issues may also hinder daily activities like brushing, eating, wiping mouth, etc. The reasons for such issues could be any of the following:

- Low tone of oral musculature
- Praxis issues i.e. difficulty in understanding and planning movements
- Sensory issues

Oral-motor training of your child becomes essential for your child to deal with these problems. Oral-motor training involves massaging or exercising gums, lips, or facial muscles to improve articulation of speech sounds, eating skills and increase or decrease the sensitivity of the mouth or face to being touched. Working on oral-motor skills will help to expand the child's diet, accept oral input from a toothbrush and the oral structures, increase the number of sounds that are produced, and assist with imitation and initiation of speech production.

Oro-motor structures :

Observe for the following in your child:

- Excessive drooling
- Open mouth posture
- Protruding tongue

These result from low tone around these structures which can be improved using the following techniques:

Massage and deep pressure over them will help improve tone. Start with massage over the outer side i.e., over the facial areas around the mouth. Use gentle, deep, consistent pressure from your fingers. Slowly shift to the inner walls of the mouth, as the child feels comfortable. Massage the inner walls of the mouth and gums in a circular fashion with your index or little finger (for infants). You may dip your finger in honey to give a pleasant sensation. You may also use a vibratory brush to massage the oro-motor structures.

Tone can be developed by having your child bite and chew hard things like raw carrots, radish, chewy tubes etc.

In case of excessive drooling, massage with finger dipped in salt and lime solution. While the salt produces excess saliva, the sour taste of the lime will force your child to suck the saliva in.

Sensory Issues :

Sensory issues related to oro-motor functions can be observed as follows:

- Biting straws when drinking or putting the straw more than 1/4 inch into his/her mouth
- Overstuffing his/her mouth while eating
- Having a limited diet
- Swallowing without chewing
- Grind his/her teeth during the day

The strategies for sensory issues related to the oro-motor structures have been dealt with earlier in the section of sensory integration.

Praxis problems :

Observe if your child can do the following actions

- Smile
- Kiss or make a kiss face
- Stick out his/her tongue
- Try to touch his/her tongue to his/her nose
- Lick jam off his/her upper, side, or lower lip
- Imitate making a funny face
- Blow out candles or blow bubbles, blow paints, blow pens, party blowers
- Bite his/her lower lip
- Show various emotions in facial expressions
- Blow his/her nose on command

Difficulty in many of these may indicate oro-motor apraxia. Incorporate each of the above activities in your child's program to improve motor-planning for gestures, eating and speech. To improve performance of these actions you may:

- Play imitation games in front of a mirror.
- Stick Cheerios, jam or chocolate at different places around the child's mouth. Ask him/ her to lick it with the tongue.
- Play 'Simon-Says" with your child to encourage imitations.

In order to improve tone around the oral structures and help the child understand and perform a variety of tongue and lip movements, oro-motor exercise must be done.

Training for oro-motor skills must initially be done under the guidance of an occupational therapist or speech therapist.

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18. Psychological Intervention

Bringing up a child with autism can be a challenging process. However, with proper knowledge and information about autism it is possible to make the process easier. As parents you require a lot of patience and perseverance throughout the journey. Every child with autism is unique, and at different ages the challenges also vary. Hence, you must be well equipped beforehand and be aware about the appropriate strategies required for your child. With behavioral issues being one of the major concerns in children with autism, a clinical psychologist/ child psychologist plays an important role in helping you and the child. A psychologist looks at what effect the behavior has on the child and may introduce a behavior management plan accordingly. They will talk through and provide solutions for various problems that you may encounter while parenting your child with autism. Here, we attempt to provide you with some guidelines which will help you get the best out of your child in the most effective and easy manner.

- **Where should you begin when managing your child's behavior at home/ school?**

Understanding your child's behavior

Firstly, understand the behavior equation that underlies all behaviors of the child. "YOU + ME + ENVIRONMENT = BEHAVIOR". Look at behaviors as positive and negative. List out all the negative behaviors you want to eliminate or modify and the positive behaviors you want them to learn. Note down all the dualities on a "strengths and weaknesses" list. Try and reason out why they display the negative behaviors i.e. what is he trying to achieve. For example; a child who has difficulty in communicating his needs might display unacceptable behaviors to draw your attention to him, like throwing temper tantrums. You must enter into your child's world and try to see the world as he/ she does. These are some situations which could trigger behavioral issues:

- Confusion or fear produced by unfamiliar people, events and situations.
- Interference or changes in daily routines
- Inability to understand explanations or instructions
- Inability to communicate needs and feelings
- Fear of specific situations or objects
- Pressure to perform tasks that are too difficult

18.1 Behavior Modification

Functional Analysis:

Functional analysis is a way of analyzing and understanding the child's behavior so that you have a clear idea about what is triggering the behavior and keeping it going. We are often able to see the behaviors but we need to dig deeper in order to work out what they mean. Once we have worked out why a type of behavior is occurring, a possible pattern may be identified. The best and most accurate way of doing this is to keep records by using a STAR chart.

STAR CHART

The National Autistic Society (UK) developed the STAR Analysis which is a helpful way of assessing what happens before, during and after an episode of unacceptable behavior. It helps reduce the behavioral problems that many parents like you face.

STAR stands for Setting , Trigger, Action, and Response:

Setting: This refers to the places in which the unacceptable behavior takes place. The behavioral issues could be prevented if there are adjustments made to the setting.

Trigger: These are reasons which may "set off" unacceptable behaviors. These have been enlisted above.

Action: Action is the behavior that is displayed by the child.

Responses: There are the events that follow an action, and are often the part of the process that can be controlled. Response to an action can indicate and influence the likelihood that the child will do the same thing at some point in future for example; giving a reward or praise etc.

Figure 18.1(1): A STAR Chart :

A STAR CHART

Date & Time	Setting	Trigger	Action	Response
2 nd May 2015 6.15p p.m.	Shopping Mall	Child along with his parents enters into a crowded store	The child starts shouting, hand flapping, closes his ears and becomes hyperactive	Ignore his behaviour or take him out of the mall and calm him down

Such a charted out analysis will help you decide how to target each behavior.

Consider Behavior and personality: Often we measure behaviors with respect to a time line or frequency. Take into account your child's personality before making statements like' "Its time to go to the mall" or "Eat quickly. It is time for school.", etc. Consider personalities that you come across each day. Identify whether your child is generally slow or fast paced, morning or evening person, he/she requires long breaks to get refreshed, unable to concentrate when kept hungry, etc. Judge his/her personality besides analyzing the behaviors.

The basics about changing behaviors:

When thinking about the dealing with a behavioral problem it is worth focusing on one area at a time rather than dealing with all at once. Narrowing the behavior down can help to understand why a particular type of behavior is occurring so that you can work out ways of changing or managing it. Trying to tackle several areas at once can make it difficult to achieve any positive changes in any areas.

Firstly, list down behaviors of your child that you think are most negative (in a descending order); such as head banging, fighting with other children or refusing to get up in the morning. The least negative behaviors at the bottom of the list should be ignored temporarily or even permanently (for example, refusing to wear anything but red T-shirts).

Certain odd behaviors that are not injurious or harmful to the child or to others, may be looked at as an indication of creative or humorous attempts to adapt (making up silly songs or drawing violent pictures). These should be accepted as part of the child's unique and positive development, even if they seem peculiar to others.

It is important to keep in mind that punishment for a wrong behavior need not necessarily be harmful always. Punishment, if given in a constructive manner could help in increasing the child's awareness about acceptable and unacceptable behaviors. For example: If your child displays aggressive behavior then you could ask him to sit in the corner of the room, or stand facing the wall. You must give him an explanation as to why he was punished and what the acceptable behavior is.

Very often you may tell your child about the behaviors which are unacceptable or what he should not be doing. Instead, make sure you explain to him about the behaviors that are acceptable. For example, saying "Please sit here next to me" instead of "Don't jump around".

It is important to maintain a consistent behavior and approach towards the child so that he does not get confused. Maintain well-defined rules which could be bent under some situations (when being rigid towards the child increases temper tantrums or hyperactivity).

The focus of any behavior intervention should always be on the development of new skills to help your child to cope with his environment and to communicate their needs. To make this change lasting the aim is to provide him with other ways of achieving the outcome, previously achieved through difficult behavior.

- **What are the various strategies for Behavior modification?**

Before addressing the specific issues, an understanding about all the available behavioral strategies is necessary. You may use the best suited strategy from the following for your child, in a variety of situations.

1. *Positive reinforcement*

This refers to strengthening of a particular behavior by following it with something desirable such as favorite foods, toys or objects, activities, praise or social reinforcement (clapping, patting, and recognition in front of others).

While starting off with the reward system, it is very important to make your child understand the concept of a reward. For children with ASD, different things could act as reinforcers, for example, objects they fancy (e.g. wires, rod), musical instruments, toys with light in them, etc. Reinforcers (like toys, stars or objects) which are used to produce desirable behaviors should not be readily available. It should be given to the child only when he or she has taken a positive step towards the desirable behavior. For example, if the child is asked to imitate an activity (e.g. brushing his teeth) and if he is able to complete it successfully, his performance would be reinforced by letting him play with his favorite toy. In this way he will understand and learn that if he displays a positive behavior then he will be rewarded.

There is a need to plan and have a variety of items to be used as reinforcements, so that the child does not get bored. Rewards should be promised only when you are fairly certain that you can provide the child with what has been promised. It is far better to offer something small and manageable, that you can continue to offer each time like hugs, claps, praise etc. instead of concrete ones like eatables or toys. Rewards of food or gifts should be used infrequently, if at all. For example, chocolates should be avoided in children who have increased hyperactivity, as it is seen that chocolates increase their levels of hyperactivity.

Reinforcement works best when it is provided immediately after the desired behavior has occurred and consistently (i.e. every time the child behaves in the desired way). During the initial stages of training, maintain a high frequency of rewards and eventually lower down and fade off, when the desirable behavior is learnt. It can gradually be faded out (decreased and then withdrawn) over time, but not too quickly.

You may design a reinforcement schedule in the following progressive manner:

- Reward frequently when the child is first learning, or when she is having a particularly hard day. Frequent reinforcement keeps motivation high! Several

Positive Reinforcement

Before	Behaviour	After
Child is asked to imitate an activity	Child is successfully able to complete the activity	Child gets to play with his favorite toy

Figure 18. 1 (2) : Positive Reinforcement



Figure 18. 1 (3) : Positive Reinforcement - High five



Figure 18. 1 (4) : Different reinforcers like rod

times a minute is okay for some children, especially when they only behave well momentarily.

- Gradually decrease how often you give reinforcements.
- Increase time intervals gradually.
- Wait until entire activity is accomplished.
- Reinforce only at difficult times of the day.

2. *Token Economy*

Token economy is a very useful way of increasing the number of times a desired behavior. Token systems are a type of positive reinforcement that involves your child collecting points, tick marks, stars, stickers or other small objects. It is seen that such short term rewards are more effective than long term rewards. For example, a reward system should be followed when the child successfully accumulates a fixed number of points or stars which could then be exchanged for larger tangible rewards such as a favorite toy or a cartoon show. Token systems usually work best for 'low functioning' children.

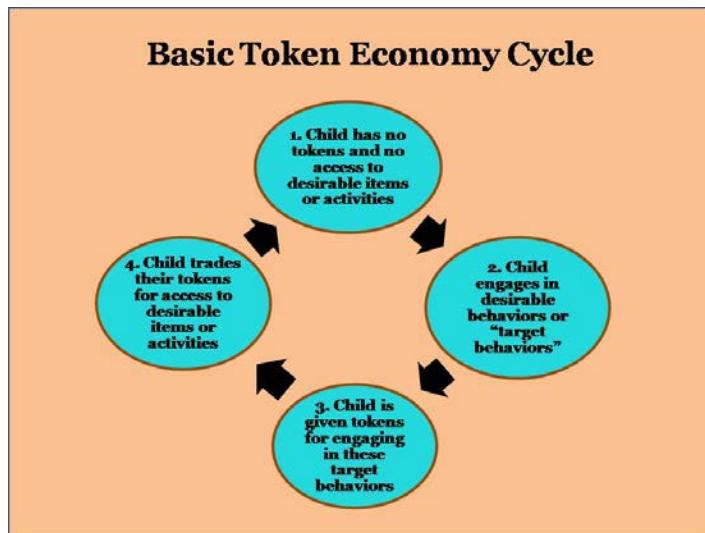


Figure 18. 1 (5) : Token economy

Activities	Mon	Tue	Wed	Thurs	Fri	Sat	Sun
Brushing Teeth	★	★	★	★	★		
Toilet Activities	😊	😊	😊	😊	😊		
Taking Bath	😊	😊	★	★	★		
Wearing Clothes	😊	😊	😊	😊	★		
Eating Breakfast	★	★	★	★	★		

Time Table

Achieved 3 stars per day: Extra half an hour of TV time
 Achieved 25 stars in the whole week: Go out for a drive or to the mall etc.

Figure 18. 1 (6) : Token Economy Time table

3. Negative Reinforcement

Negative reinforcement reduces a negative behavior and as a result the child behaves in a desirable manner. An already existing aversive (disliked) condition can be taken away when the child performs a particular behavior. For example, if you have set a restriction on watching a particular cartoon or having chocolate, you may lift the ban if your child displays a good behavior (e.g., behaves appropriately in front of your guests, or eats his lunch neatly by himself). Again, explain to the child the association between the behavior and the reinforcer. Choose appropriate reinforcers that the child truly identifies as negative. Negative reinforcers work better in slightly high functioning children with autism.

Negative Reinforcement

Before	Behaviour	After
Child isn't allowed to watch T.V.	Child tries to initiate social interaction with children in the garden	Child is allowed to watch T.V. for $\frac{1}{2}$ hour for 1 week.

Figure 18. 1 (7) : Negative Reinforcement

DEALS AND CONTRACTS

Contracts and deals can be used effectively to manage behaviors in school and at home. Pairing "If,..." statements with "then,..." statement provide for clear definitions of behavior and consequence. They help teach an important life lesson; "Work is equal to reward". You may be using them informally but following some simple rules will make them effective and easy.

- Make the contract visual by writing it down or representing with picture cards. Frame it as "working for-----" card with the reward as a picture.
- State the rules in clear and concise language. Do not use vague terms like "good". Structure and quantify your contract rules so that the terms are clear to both sides, you and the child.
- Start small and expand eventually. One task equals one reward. Don't raise the demands or stakes too high too suddenly.
- Confirm that your child has understood the expectation and the possible consequence.
- Honor the deal. Do not fail to keep up to your own terms. Never modify the terms on-the-go. Do not add more to your demands just because he/she managed to complete well in time. This will just upset him/her.
- Avoid setting terms and conditions that are definitely not achievable for the child as well as you. Be pragmatic.
- Think of alternative rewards you could provide at least for an attempt. Remember, it is ok to fail once in a while. Acknowledge the effort with a smaller reward and encourage better performance the next time.
- Do not make the contract sound like blackmail. Make it positive instead of using it to prevent or stop negative behaviors. Rewards are not to be assigned for stopping or refraining from a tantrum or negative behavior.

4. *Punishment*

This involves the use of an unpleasant response to reduce the occurrence of an undesirable behavior. Punishments should not include smacking, shouting or physical restraints. Also, as children with autism could have altered pain perceptions, for example, a needle prick or a severe wound would not hurt or pain them as compared to average children. However, constructive punishment that do not harm or hurt the child may be used in selective situations where other methods have not worked. Constructive punishments are of 2 types such as: Positive punishment like time out and negative punishment like withdrawal of a pleasurable object or enjoyable activity.

Children with ASD may learn many undesirable behaviors as they are not able to differentiate between right and wrong. For example, when the child with autism is shouted at or he is smacked for doing something wrong, he sees that it's all right to be aggressive (as you just were with him). As the child grows up he/ she may behave aggressively towards others. Thus, any form of punishment must be used with caution.

Some research also suggests that punishment strategies do not always work and these are not effective ways of promoting learning.

5. *Shaping*

In this strategy, the desired behavior, has to be broken down into clear steps and should be taught to the child step by step (one at a time). Eventually, all the steps need to be put together to create the desired behavior or task accomplishment. For example: teaching a child to eat independently. Initially, reinforcement might be needed to teach him to reach for the spoon. Once this stage is mastered, reinforcement would be held back until the child actually picks up the spoon and so on until the child takes the food into his mouth, chews it well and swallows it, without any spills.

6. *Chaining*

Chaining is a teaching technique that consists of breaking a task down into small steps and then, teaching each specific step within the sequence. This technique is helpful when your child needs to learn a complex, routine task that is repetitive. For example, the child may need to learn all of the steps in the process of using the bathroom or putting on shoes etc.

There are two types of chaining techniques, "forward chaining" and "backward chaining." The forward chaining technique moves the child from the first part of the task to the end and backward chaining technique moves the child from the last part of the task to the beginning. The decision to use either a forward chaining" or backward chaining" is dependent on the child's ability and the task at hand.

Steps under forward chaining:

- Identify the target behavior
- Analyze the task to determine each individual step
- Teach and reinforce the initial step in the skill
- When the first step is mastered, teach and reinforce the second step in conjunction with the first step (i.e. practice first and second step together)
- As each successive step is mastered, add the next step in the skill series until the child is able to demonstrate the entire skill without your support

For example, while teaching your child to brush his teeth, you may begin with taking the toothbrush and applying tooth paste on it. Once this is mastered you may attempt applying toothpaste followed by taking brush to the mouth and teaching side to side and top to bottom movements of the brush over the teeth. Similarly you would chain the third step to the above two.

Steps under backward chaining:

- Identify the target behavior
- Analyze the task to determine each individual step
- Teach and reinforce the last identified step in the skill
- When the final step is mastered, teach and reinforce the next-to-last step (i.e., the step before the last step)
- As each successive step is mastered, add the previous step in the skill series until the student is able to demonstrate the entire skill without your support.

For example, while training your child to brush his teeth, complete the entire task and only get him to do the last step of rinsing his mouth with water and spitting it out. Next, you again do the entire task except the last two steps, i.e., you teach him to rinse the tooth brush and then rinse his mouth with water and spit it out. Slowly reduce the number of steps that you initiate for the child.

7. *Prompting*

This technique is used to help a child learn new skills by providing the level of assistance needed to finish a task or activity. Prompts could be physical, non-verbal (gestures), verbal or environmental. Prompting paired with reinforcement helps strengthen each stage of learning a particular skill. Prompts should be faded over time as the ultimate goal is for the child to complete a task independently.

For example, if the child has to be taught to wave "bye-bye", you could use a partial prompt (physical) by tapping the elbow of the child to raise his hand and to wave bye-bye.

8. *Extinction or planned ignoring*

This refers to the strategy where undesirable behaviors are ignored rather than ignoring the child. This is because responses provided by others, such as attention or provision of an object or activity may be maintaining an unwanted type of

behavior. Planned ignoring involves providing no response to the behavior, including verbal comments, body language, facial expression or eye contact.

It is important to remember that planned ignoring can be used with a number of behavioral difficulties but it should never be used when there is risk of harm to the individual or others.

Extinction / Planned Ignoring

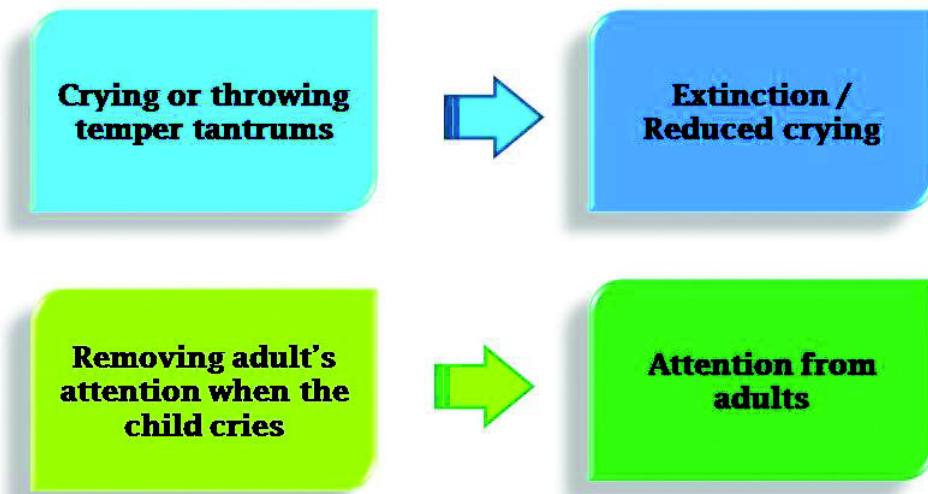


Figure 18.1 (8) : Extinction / Planned Ignoring

9. *Redirection*

Redirecting your child's attention to a preferred topic of conversation or activity can be an extremely effective way of preventing a situation from getting worse, especially when your child starts to get agitated. Having started to use your STAR recording charts (explained before in this chapter), you will have a good understanding about things that act as triggers, setting off a particular type of behavior in your child. Shift your child's attention to more enjoyable and productive activities when you sense such triggers. Relaxation strategies and anger management techniques can be used to redirect and refocus your child when distressed.

BE PROACTIVE, NOT REACTIVE

When managing behavior ensure that you control the situation, rather than allowing him/ her to direct it. Proactively plan, rehearse and use the above strategies instead of reacting impulsively to the behavior at hand. Recognize and refrain yourselves from your own reactive behaviors as they are unhealthy for you as well as the child.

Do not give in out of fear that something horrible may follow. This is as good as rewarding the unwanted behavior.

Do not succumb to your feeling of guilt. You may realize that your child's behavior is a result of your faulty behavior or communication. This cannot change the given consequence of his/her action, retrospectively.

Repeated warnings are like empty threats. Make one clear statement that is a well understood warning which ensures immediate following.

Never beg for compliance. Begging and bribery shift the control back to your child. Refrain from resorting to these.

10. Time out

You can define what is sometimes called a 'behavioral contract'. Explain clearly to the child what is going to happen and why. During an activity or a lesson in class if the child displays unacceptable, uncontrolled behaviors or aggression towards others, you may pull him out of the scene/ situation for a short time period. For example, ask him to stand in the corner of the room. The child must understand that this is a time for him to cool-off and settle down and avoid harming self or others. If a time-out area used must be identified as an uninteresting but safe space where there is no risk of your child harming himself.

How can you help your child deal cope with transitions and changes?

- Children with autism yearn for sameness and routine. A change in their routine could be catastrophic. They would try their best to stick to their routine or would throw temper tantrums. It is seen that children with autism work better and learn better with people who are more structured (follow set simple patterns) in their daily routine. The following are a few strategies that may help them accept and adjust to transitions:
- Begin with small changes to their routines and then slowly progress to larger and more number of alterations. This will help them adapt slowly and in a comfortable way.
- Dim the lights of the room, when a new activity is being presented to them as this will help the child focus better and avoid distractions.

- Give prior explanation to your child about the possible transition. Helping them understand why a particular change is taking place would help them be prepared beforehand, rather than having a flaring temper after the change has occurred.
- Make the transition as enjoyable and as stress free as possible because otherwise the child's autistic features will shoot up.

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18.2 Applied Behaviour Analysis

Applied behaviour analysis (ABA) is a specific form of behaviour modification. It is defined as the process of systematically applying interventions based upon the principles of learning theory. ABA is used to improve socially significant behaviours to a meaningful degree.

ABA is a science which includes general laws about how behaviour works and how learning takes place? It is based on the set of principles that form the basis of behavioural treatments. The principles work on the belief that influencing a response associated with a particular behaviour may cause that behaviour to be shaped and controlled. This basically means that a behaviour which is rewarded is more likely to be repeated than a behaviour which is not rewarded. ABA is a mixture of psychological and educational techniques which are tailored to meet the needs of each individual child and alter his undesirable behaviours.

ABA is considered an evidence-based "best" practice treatment by the US Surgeon General and by the American Psychological Association. "Evidence based" means that ABA has passed scientific tests of its usefulness, quality, and effectiveness.

History of Applied Behaviour Analysis...

The use of ABA as a therapeutic method for children with autism began in the late 1960's. In 1987, a cutting - edge research study on children with autism found that a large, substantial, intellectual and academic improvement could be gained from an intensive (40 hours per week) and early intervention ABA programme. Since then, ABA has become the leading research supported therapeutic treatment for Autism. The popularity of this therapy has lead to many improvements in the therapy principles and strategies.

In addition to benefiting children with autism, research has also shown that ABA can greatly benefit individuals with Intellectual disability, Down's syndrome, Traumatic brain injury, Attention deficit hyperactivity disorder, Obsessive compulsive disorder and many other disabilities as well as treat problem behaviours in typically developing children.

Basic principles of Applied Behaviour Analysis:

ABA lies on the principles of behaviourism and more specifically lies on the theory of operant conditioning. It involves giving a child a stimulus (a request) and then provides consequence in terms of either a reinforcer or a punisher. For example, a child if displays socially adaptive behaviour he gets stars, tokens or verbal praise. The consequence of the stimulus is a punisher when he does not display this appropriate behaviour. Punisher could be not giving verbal praise, or with holding the desired toy or activity of the child.

Thus,

- A reinforcer will increase the probability of the response; a Punisher will decrease the likelihood of the response.
- A reinforce and a punishment is different for different child
- Functional assessment of the reinforcers and punishers is essential as it helps in knowing the effectiveness of them on the child and shaping their behaviour.

Will ABA benefit my child?

Is your child...

- Having self - injurious behaviour?
- Having repetitive and ritualistic behaviour?
- Having aggressive behaviour?
- Having temper tantrums?
- Having difficulty in communicating his needs?
- Having difficulty in learning new things?

If your child has any of the above mentioned problems then an ABA-based approach to behavior intervention may be useful. ABA can not only extinguish these behaviours but also promote alternative pro-social behaviours simultaneously. ABA is helpful in teaching academic, social and life skills (for example, shopping or work skills). The process of ABA is successful as it breaks complex tasks into smaller parts making them less daunting for the child. The proper application of behaviour modification principles also prevents behaviours from becoming problematic. ABA can also be used to train a child to learn a new adaptive behaviour, such as dressing and toileting and to promote functional communication.

All behaviours, whether they are being observed or taught, can be broken down into 3 parts:

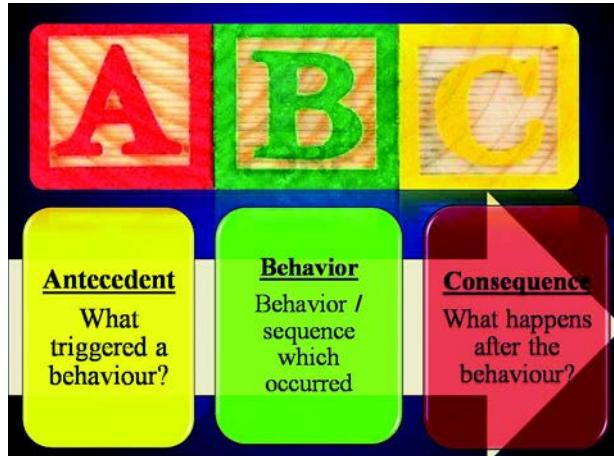


Figure 18.2(1): ABC Principles

The consequence is whatever the behaviour accomplishes, for example it can be getting attention (negative or positive) or relief of stress. The consequence is not always obvious, especially in the case of stimming behaviour (odd behaviours the child does such as arm flapping or repetitive actions), which is why keeping data is helpful to identify what the function of the behaviours are, as well as what triggers them.

Applied Behaviour Analysis Assessment:

The ABA assessment session consists of carefully observing and assessing the child's behaviour:

- Which behaviours are displayed by the child?
- When these behaviours are performed?
- At what rate the behaviours are occurring?
- What happens before and after the behaviours?
- What purpose does the behaviour serve?

Skills that are to be promoted are broken down into small sequential steps. The ABC principles of behaviour intervention are used to teach the child each step, :

- A (antecedent): Each instruction is given clearly, in as few words as possible. Assistance is provided; for example prompting through demonstration or physically guiding.
- B (behaviour): An appropriate behaviour is observed,
- C (consequence): A consequence is an outcome that will reward the child and increase the likelihood that the behaviour will be repeated again in the future, also called a positive reinforcer.

Strategies of Applied Behaviour Analysis:

1. Discrete Trial Teaching:

Discrete Trial Teaching (DTT) is one of the methods of teaching a skill to the client. In this method, a skill to be learnt is broken down to small discrete steps and repeated lessons or trials are taught one-to-one. Each trial consists of a prior, a "directive" or request for the individual to perform an action; a behaviour, or "response" from the person; and a consequence, a "reaction" from the therapist based upon the response of the person. Positive reinforcers are selected by evaluating the individual's preferences. Successful completion of each step results in positive reinforcement. For example, to teach a child with autism colour recognition, Discrete Trial Teaching can be successfully used in the following way:

Discrete Trial One:

1. Therapist places one red and one blue card on the table in front of the child
2. The Therapist then says "point to red"
3. The child responds by pointing to the red card

4. The Therapist would say "That's right! Great job!"
5. There would be a very short pause before a new discrete trial would begin

Discrete Trial Two:

1. The therapist places one red and one blue card on the table in front of the child
2. The Therapist then says "point to blue"
3. The child responds by pointing to the blue card
4. The Therapist would say "You're right! That's Brilliant!"
5. There would be a very short pause before a new discrete trial would begin

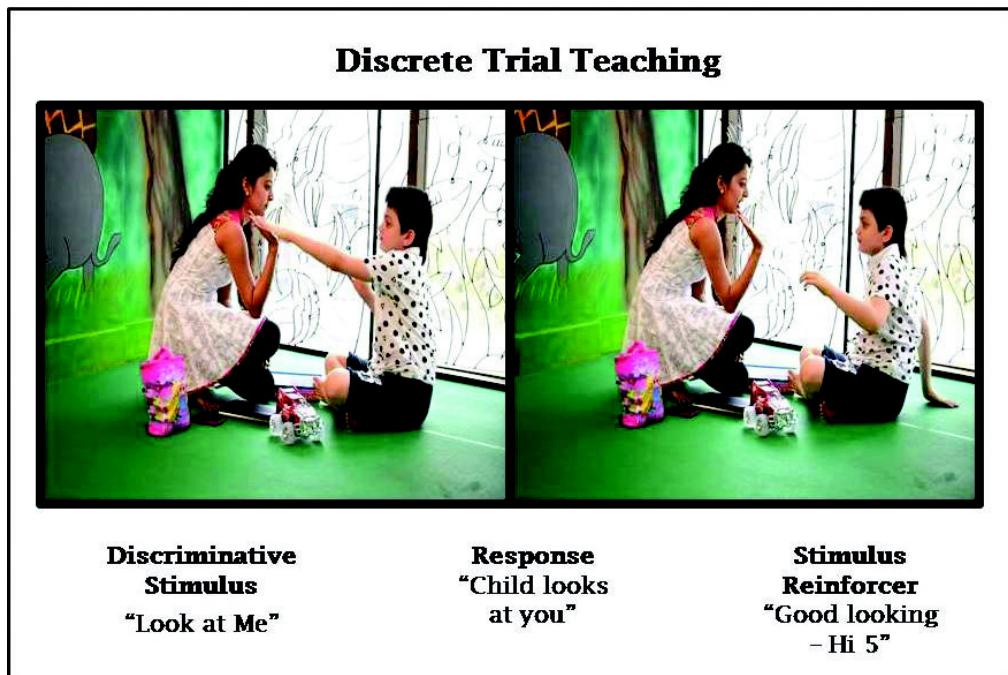


Figure 18.2(2): Discrete Trial Teaching

Initially, the child could be given something concrete as reinforcement. Stars, Tokens can work well as reinforcers. However they need to be faded as soon as possible and replaced with praise or hugs

Parent training is a necessary part of an effective ABA-based program. The child's progress is closely monitored by the collection of data on the performance of each trial. After a skill has been mastered, another skill is introduced, and the mastered skill is placed on a maintenance schedule. A maintenance schedule allows for periodic checking so that the child does not regress in mastered skills. Discrete trial training is a technique that can be an important element of a comprehensive educational program for the individual with autism spectrum disorder. It is regarded as effective treatment method because these children have difficulty in

observing their environment and learning from it so teaching these children basic concepts and skills through these short scripted trials proves to be beneficial. Also this one on one approach can make the training more customised according to the need of the child.

2. *Pivotal Response Therapy:*

Pivotal Response Therapy (PRT) has been developed by educational psychologists Robert Koegel, and Lynn Kern Koegel at the University of California. This method helps in improving the play behaviour, socialization skills and reducing self stimulatory behaviours. It works on the principal that if the "Pivotal" areas of a child's development such as his motivation, self management and initiation of social interaction skills are focused on. This will produce improvements in other major broad areas as well such as socialization, communication, behaviour and academic skills.

The two primary pivotal areas of pivotal response therapy involve motivation and initiation of activities. Three others are self-management, feelings and the ability to respond to multiple signals, or cues. Play environments are used to teach pivotal skills, such as turn-taking, communication, and language. This training is child-directed: the child makes choices that direct the therapy. Emphasis is also placed upon the role of parents as primary intervention agents.

The effectiveness of pivotal response therapies have now been proven and ongoing research of its effects on autistic children is being conducted. Pivotal response training is specifically designed to increase a child's motivation to participate in learning new skills. Pivotal response training involves specific strategies such as

- " Clear instructions and questions presented by the therapist
- " Child choice of stimuli (based on choices offered by the therapist)
- " Intervals of maintenance tasks (previously mastered tasks)
- " Direct reinforcement (the chosen stimuli is the reinforce)
- " Reinforcement of reason for purposeful attempts at correct respond
- " Turn taking to allow modelling and appropriate pace of interaction

Research indicates that children with autism who are developmentally ready to learn symbolic play skills can learn to engage in spontaneous, creative play with another adult at levels similar to those of language-age matched peers via pivotal response training.

3. *Reciprocal Imitation Training:*

Imitation is one of the most important or 'Pivotal' skill in the development of a child. Reciprocal imitation training was developed to teach spontaneous imitation skills to young children with autism in a play environment; however, this intervention technique has also been shown to increase pretend play actions. Reciprocal imitation training is designed to encourage mutual or reciprocal

imitation of play actions between a therapist and child. Once the child learns to imitate, he or she can observe the environment and learn new things. However a child having autism or Autism Spectrum Disorder lacks this skill. Thus building up this skill will help improve the child's social-communication skills.

In Reciprocal Imitation Training (RIT) you imitate the child and then the child imitates you. Through this the child understands that you are interested in playing with him in his way. It also helps in teaching the child appropriate play skills, gestures, language when it is your child's turn to imitate you.

Following are the ways in which you can imitate your child:

- Sit Face to Face
- Imitate play with toys: For example, if the child is rolling the car or spinning wheels, imitate him.
- Imitate play through gestures : For example, if your child is running , walk with a fast pace abut take the same path
- Imitate Vocalization: for a child, who has just begun using letters, imitate those.
- Do not imitate aggressive or any kind of behaviours that are destructive or harmful.

4. *Chaining:*

Chaining is a technique in which the behaviour or a skill to be learnt is broken down into small steps or units. For example, a child who has to be taught brushing can breakdown the activity of brushing into small units. Initially he can learn to take a tooth brush in his hand, then a tooth paste, removing the cap of the tooth paste, squeezing it out on the brush and then putting it inside the mouth.

5. *Prompting:*

In this, the therapist gives assistance to encourage the child to give the desired response for example, to teach a child brushing activity. The therapist can prompt the child verbally and ask her to remove the cap off. Prompting can be done also through physically demonstrating what has to be done or through visual cues such as pointing out.

6. *Fading:*

Fading away the prompts is essential so that the child does not become overly dependent on the prompts. When a new behaviour is learnt, the prompts are faded. For example, learning to open a tooth paste lid earlier required physical demonstration, pointing out which were gradually faded and replaced with just a verbal request.

7. Generalization:

Once the skill has been learnt perfectly, it needs to be applied to generalised set up for example, if the child has mastered his / her colour recognition skill, the therapist will help him / her generalize this skill by asking the child to recognize colours in day to day events.

8. Self-Management Training:

Self-management has been developed as an additional option for teaching children with autism to increase independence and generalization without increased reliance on a teacher or parent. Self-management typically involves some or all of the following components:

- Self-evaluation of performance,
- Self-monitoring &
- Self-delivery of reinforcement

Ideally, it includes teaching the child to monitor his/her own behaviour in the absence of an adult. This therapy uses a self-management treatment package to train school-age children with autism to engage in increased levels of appropriate play. In a study children displayed very little independent appropriate play before training, and typically engaged in inappropriate or self-stimulatory behaviour when left on their own. With the introduction of the self-management training package, the children increased their appropriate play in both supervised and unsupervised settings, and across generalization settings and toys. Decreases in self-stimulatory and disruptive behaviours were maintained in the unsupervised environments.

9. Video Modelling:

Video modelling makes use of predictable and repeated presentations of target behaviours; however, these behaviours are presented in video format, thus reducing variations in model performance. Video modelling has been shown to improve various skills in individuals with autism, including conversational speech: verbal responding, helping behaviours, and purchasing skills. This medium has also been claimed to increase vocabulary, emotional understanding, attribute acquisition, and daily living skills.

Video modelling interventions have used both self-as-model and other-as-model methods. In the first performance, individuals act as their own models, and the video is edited so that only desired behaviours are shown. The second and perhaps more essential method of video modelling employs taping other individuals, typically adults or siblings, performing target behaviours.

Video self modelling has been theorized to be more effective than traditional video modelling because it may promote increased attention from the individual, although factual studies have not substantiated this claim. Applications of video modelling as an intervention technique are now being extended to teaching and increasing play in children with autism.

Advantages of Applied Behaviour Analysis:

Applied Behaviour Analysis is evidence based and it has proved to be an effective intervention in teaching children and adults how to manage their challenging behaviours.

Applied Behaviour Analysis helps to:

- Increase appropriate behaviours
- Teaching new skills
- Regulating self by controlling self stimulatory behaviours
- To generalize the appropriate learned behaviour
- It helps your child learn what "to do" instead of just learning "to stop doing something"
- Improve ability and performance on tasks
- Reinforcement procedures increases on-task behavior or social interactions and reduce behaviors like self-injury or stereotypical behaviour
- It helps teaching children self-control and self- monitoring procedures to maintain and generalize job-related social skills

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18.3 Meltdown

The dreaded meltdown... How to handle it?

A meltdown is a stressful experience for the child and everyone around. Simply defined it is the sheer loss of control over one's behavior. It is exhaustive, frustrating, loud, scary and at times, risky. It is the ultimate cry for help. It means that the child needs your help to regain his composure. Carefully observe your child if they are experiencing meltdowns. Does the meltdown have a brief period before onset where your child spaces out? Do they get totally uninvolved with their environment prior to a meltdown? What are the signals? What are the behaviors seen during the meltdown? Look out for dangers to the child and others.

What should you do?

- When your child sets into the meltdown, remove him from any areas that could harm him or he could cause harm. Glass shelves and doors may become the target of an angry foot. Try to avoid having objects at hand to throw at people. Avoiding injury is the top priority during the meltdown.
- Don't try to reason with them. They aren't listening and too much talking just adds to their sensory overload. There will be plenty of time to discuss it after they calm down. Remember, their behavior doesn't have to be dealt with immediately. You may have to physically restrain the child until the extreme violent feelings have passed, due to fear of him hurting himself or others. Just wrap your arms around him/ her, while he/ she is fighting to get away. Some children calm down with slow, gentle rocking.
- Being able to handle a meltdown in public is equally important. Parents commonly report an increased incidence of meltdowns in public places. Stores, malls, fairs, the circus, the theatre, wild birthday parties-anywhere there are a lot of people, activity, and noise increases the odds of a meltdown. You may choose to avoid such environments. Some activities cannot be avoided. Strategies to handle these must be developed. For some reason, in public, many people feel it is their duty to point out (sometimes subtly and sometimes loudly) the mistakes you are making in raising your child. This is a common occurrence for parents of challenged children. Just remember, stay calm and handle the situation in a manner to best fit your child's needs regardless of the disapproving looks or comments. You can't change the world but you can affect your child's feelings and learning experiences which is far more important than being concerned about the opinions of strangers.
- Parents of kids with special needs will have more peace of mind if they can develop a thick skin. But regardless of how thick-skinned you are, an insult to your child hurts immensely. Keep in mind that some people are receptive to learning and you may have a chance to educate someone about autism. You can lightly apologize

for the disturbance and politely offer a brief explanation of "he is disabled," and leave it at that.

Defusing a meltdown in its early stages is often the best way of handling it. Once these children reach an age where they understand their irritation and anger can lead to a meltdown, do not want a meltdown. Things will irritate them and anger them; just like everyone else in the world has their triggers (autistics may have a couple more). Unfortunately, they will not be able to control it once it reaches a certain threshold. Just remember, if your child is of average intelligence you are dealing with someone who has the ability to stop the behavior if it is caught in time. Everyone in regular contact with the child should learn the signals and be able to assist the child in their selected defusing techniques. The child needs to be taught techniques and practice them in calm situations. The goal is to not reach the break point of no return. Not only does the child need to be taught defusing techniques, they need to be taught how to recognize the early stages. The following ideas can be tried and tested:

- Recognize the signs that a meltdown is impending.
- Usually there is a trigger before the meltdown-determine what the trigger is.
- Choose your battles wisely. If the trigger is fairly insignificant, you might seriously give them what they think they need. Don't go to war over a 'bag of peanuts'. Peanuts are small price to pay for avoiding a meltdown.
- If the trigger is something that is not reasonable to resolve, try to distract the child or divert their attention. This may or may not work. They just may move their obsession to something new.
- Always try to keep a new toy or puzzle with you for outings to restaurants, doctors offices, church, etc. A handheld puzzle, can work well.
- As you are working to distract your child, speak softly to them about their behavior and let them know that it needs to stop. If you have done your homework during calm times and taught the child about acceptable and non-acceptable behavior, use the same words you did earlier. Stay calm and try to limit the length of your lecture.
- With a very young child or one who does not understand they need to defuse a meltdown, it is more challenging. Distraction is still your best tool, reason will not work and probably only confuse the child more. Always remember, these children are already in sensory overload mode. Remaining calm is extremely important.

You will not always be successful in helping a child defuse. If the cycle progresses and he reaches the point-of-no-return, you have two options. You can ride it out or you can remove the child from the environment triggering the discomfort. If you have gone through the steps above, the child has chosen to continue to meltdown of his own free will. Sometimes it's a learning experience to ride it out.

Persistence, practice, patience, and consistency are the ingredients to succeed in teaching your autistic child acceptable social behaviors. As the child grows and understands the

norms he/she will be able to control and monitors his/her own behaviors. An internal locus of control will develop eventually that works best when the child needs to function by himself. The above management strategies work best during the early, formative years. They form the basis for education, social skills training, relationships building and preparing for employment.

Do not confuse meltdowns with temper tantrums. There are differences that are easy to spot if you observe carefully.

During a meltdown, a child with autism does not look or care, if those around him are reacting to his behavior. A child having a tantrum will look to see if their behavior is getting a reaction.

A child in the middle of a meltdown does not consider their own or others safety. A child in the middle of a tantrum takes care to be sure they won't get hurt.

A child in the meltdown mode has no interest or involvement in the social situation. A child who throws a tantrum will use the social situation to their benefit.

Meltdowns seem to move along under their own power and wind down slowly. With a tantrum, it will end suddenly when the situation is resolved.

A melt down gives the feeling that no one is in control. A tantrum will give you the feeling that the child is in control, although they are pretending they are not.

The meltdown usually begins when a specific want has not been permitted and after a point, nothing can satisfy the child until the meltdown has run its course. A tantrum is thrown to achieve a specific goal and once the goal is met, things return to normal.

Points To Remember During A Meltdown :

- Stop the activity that is ongoing. Do not try to teach anything.
- Use more concrete, simple language during a more stressful situation.
- Assign one person to responsibly communicate with the child, one-on-one, every time the situation goes out of control. Too many people talking simultaneously could only aggravate the problem.
- Plan and rehearse ahead your means of handling the meltdown.
- Time-outs work effectively for you and the child.
- Let loose whenever possible to avoid or curb the meltdown. Be affirmative when absolutely necessary. For example, you may continue to insist on putting on the seat belt but not on putting the books back on the shelf.

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19. Speech Therapy

Introduction :

Usually, the first thing a parent says to a professional dealing with autism is "My child does not have speech. Please teach him to talk." In the desperation to see your child verbalize with words and sentences, you fail to connect with him/her. Thus you are unable to notice all the other means of communication. Whether expression comes through spoken language, or picture cards, a communication device, gestures or sign language; it is all communication. Each child has something to say to us. It is our responsibility to listen in a way that ensures that they are heard and understood.

- Keep in mind the basics before getting to in depth training.
- Be emotionally available to your child. Let him know- "I am here for you."
- Do not forget to establish contact with your child before speaking or communicating: Physically move to the child's level. Squat down, kneel and position yourself so that you are face-to-face.
- Establish attention with contact, visual props; ensure that the child is oriented towards you.
- Use gestures meaningfully. Avoid waving in the air while you talk. Use gestures to accentuate the clarity of your communication, not to confuse the child or distract him.
- Do not use complex sentence forms and expressive forms of language. Stick to literal and concrete sentences.

INSTEAD OF SAYING...	SAY...
This is a cat.	This is a picture of a cat.
Put these into the cupboard	Put the books into the cupboard.
This is red.	This is a red flower.
Let's go.	We are going to the store now.

No running in the corridors.	Please walk to your classroom.
If you don't finish your homework, you can't watch television.	After you finish your homework, you can watch television.
Hold your horses.	Do not hurry. You will get your turn to play.

What is the Role of Speech and Language Therapy in Autism?

A Speech and Language Pathologist (SLP) works with children with autism to address the following:

- Helping the child to understand communication
- Facilitating understanding of spoken language and situation expectations
- Giving the child something to talk about
- Giving the child a means of communication
- Giving the child a reason to communicate

The speech therapist works with the child and his/her family to facilitate effective communication among them such that it benefits the overall development of the child. The therapist deals with two categories of children namely, verbal and non-verbal. Diagnostically, there is no clear line of differentiation between verbal and non-verbal individuals with autism. In Verbal autism, children have language abilities which may not necessarily be correct with respect to language rules, grammar or meaningfulness. Sometimes they may just string words together to form a random sentence. The SLP helps these children convert their vocabulary into effective and meaningful communicative sentences. Non-verbal autism is more challenging to treat. About 10-15% of people with autism spectrum disorders are truly non-verbal, meaning they don't communicate using spoken words. However, it does not mean that they don't communicate at all. Many do communicate at different levels of complexity using keyboards, assistive devices, picture cards and sign language. Such training may be provided by a SLP.

The SLP also works on their cognition, understanding abilities, verbal repertoire and functional communication. Echolalia i.e. repetition of words or others' sentences is also tackled. During the first 3 years of life the brain is developing, thus it can be easily molded into any form. Hence it is the most important period for acquiring speech and language skills. Children learn languages faster during this period with adequate stimulation and exposure. Managing a child with autism at school or at home is a problem you must definitely be facing.

Management is based on the core concept of a multi-sensory approach [auditory, visual, tactile, sensory, and kinesthetic].

The bottom up process for speech development:

An eight-level hierarchy of supports make it possible to build the foundations for

breathing, voice and articulated speech. This hierarchy will help you understand that firstly, no spoken language does not mean no communication and secondly that, a step wise process must be followed to help children on the spectrum find their words.

Level 1- Deep breathing/ exhalation.

Level 2- Voice/ vocal production.

Level 3- Intonation.

Level 4- Starting, maintaining, and stopping sound.

Level 5- Vowel sounds.

Level 6- Consonant sound development.

Level 7- Sequencing words.

Level 8- Purposeful speaking.

A speech and language pathologist will help identify at what level your child is and take him through each of these levels with the help of appropriate techniques.

In the following sections we are going to discuss how you could work on your child's speech, communication, social skills and concept learning for children with verbal and non verbal type of communication. Initiating basics at home is a pre-requisite to achieve normal speech and language development.

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19.1 How Can You Improve / Facilitate Verbal Communication?

A) Receptive language (understanding speech, following commands):

Comprehension of simple one-word command is also affected in some children. Use flash cards/ pictures to explain simple action verbs like standing, sitting, sleeping, smiling, crying, laughing, playing, bathing, eating etc. These can be followed by picture matching, imitations and situation associations and reinforcements.

After working on action verbs, the child must identify commonly used nouns i.e. objects (light, fan, table, chair, door etc), fruits (which the child eats), vegetables (those which are commonly prepared at home), common animals, basic colors, basic shapes etc.

Here again, picture cards and real objects are a must because visual, auditory, tactile stimulation helps children to understand concepts faster. Follow the similar pattern of first matching, then recognition of a particular shape/ object and then naming the shape/ object himself.

Prepositions like on, under, above, inside, outside, up, down, left, right, front, back are also difficult for these children to comprehend. This is not only because they do not understand the language rule but also due to their poor orientation abilities. Hence, a more practical approach is necessary to teach prepositions. For example, keep things that your child recognizes by name (a soft toy) at different positions- to his left/ right, above the bed, under the bed, etc., and ask him to look for it. Focus on and repeat practice for a particular preposition along with verbal prompts, visual clues so that child can locate faster.

You may do a matching exercise, but here it will be of a picture to a spoken word. Therefore, comprehension of the preposition is very important. This may take longer time than any other task but be patient and practice with lots of practical examples and with adequate reinforcers. You may also use imitation and rhymes to teach your child the concept of prepositions and the orientation of himself with respect to the objects around him.

Understanding and learning the use of adjectives independently is difficult for the child due to its abstractness. Yet, simple adjectives like good, bad, beautiful, dirty etc. can be worked upon by using picture cards and also with extensive use during communication with the child. Once achieved, these adjectives can be used as reinforcers as well. But it must be remembered that adjectives are understood much after nouns, verbs and prepositions. Talking extensively and with overemphasis helps recognition of common nouns and adjectives.

Build your child's oral and written language with the help of wordless books. They stimulate enjoyable reading and allows for creativity and imaginative thinking as the pictures flow; and because there are no words their interpretations are always right. The child has control over the story and this boosts his/ her self esteem. Preview the book for age appropriate content. Do not go by the age recommendations on the books as they are directed towards typically developing children. Pick familiar themes for young children and progress to newer ones as the child grows.

B) Comprehension of simple two word commands

It is important to give short, clear and simple commands like sit down, get up, come here, let's go etc. Pictures cards depicting meaning of the commands have to be used.

Demonstrate to the child by first saying the command and then actually following it yourself. Then, encourage child to imitate you and follow the command along with you.

Picture cards should be made carefully to depict every action in sequence. For example, "Come, sit". Here, the first picture should depict a child standing little far from the person giving the command. The second picture should show the child as having come closer to the person and finally, the third picture should show the child seated beside the person. Sequencing pictures for each command can be practiced followed by actual performance. Here again, adequate reinforcement is necessary.

C) Comprehension of three to four words command

The approach remains the same as before. Use sequence picture cards with commands, where the addition of nouns will increase the sentence length. For example, shut the door, switch on the fan, bring a glass of water etc.

D) Expressive language (Spoken language, expression with words/ sentences)

Speech of a child with autism comprises mostly of non-meaningful words or repetitions of words or phrases. To have your child use meaningful words for expression and responses is a complex task.

To achieve this, first encourage your child to vocalize maximally. For example, make him say /a/, /e/, /u/, /pa/, /ba/, /ma/, /la/, /ka/, /ta/, /da/, /na/, etc.

Show him the tongue and lip placement for producing the above mentioned syllables. If required help your child in closing his lips to produce sounds of /pa/, /ba/, /ma/. This way the child will learn the correct manner of producing a particular syllable.

Once the child produces any of the above syllables, help him/her use those syllables to communicate, for example, requesting for food, water etc.

The next stage is combining two syllables like /mama/, /papa/ and saying it aloud every time he sees you (mother or father). In this way syllables can be combined to make a word production.



Figure 19.12 (1): Recognition of fruits



Figure 19.12(2): Spotting the desired alphabet 'E'



Figure 19.12(3): Meaningful counting



Figure 19.12(4): Identification of colors & shapes

Initially, encourage all kind of verbal production; later, try to shift towards meaningful words.

While talking to your child, speak loudly and clearly using intonation. Open your mouth wider so that the child can see tongue and lip movements for imitation. When your child attempts to imitate, reinforce the positive behavior with a toy or an eatable.

To tackle echolalia (repetitive speech) the child needs to be diverted through some constructive activity so that child's attention gets diverted. Do not respond to your child's verbal repetitions by saying "don't say that" or "stop it". Instead, just give the child an activity he enjoys. For example, water activity, dance, music etc.

How can you work on your child's Concept formation and Cognition?

a) Alphabet and number recognition

Big, colorful and attractive pictures along with alphabets could be used so that the child can understand 'A' for 'apple'. Here, use only one picture and alphabet at a time. Make charts and stick it on the wall in his room. This way the child will look at it repeatedly and will start recognizing the alphabets.

Pointing to the alphabet when asked for the letter 'A', is the first step. Later ask the child to point to the letter when shown an apple. Once this is perfected, go on to the next alphabet. After working on three alphabets, ask the child to do the matching exercise (list out the letters on one side and the objects starting with those letters, randomly on the other side).

Following matching, the child must begin naming the alphabets and their associated words/ objects. When newalphabets are being practiced, do not stop rehearsing the previous ones. Adequate reinforcement will encourage your child to learn faster and better.

Number recognition has to be worked upon with practical and meaningful counting. Show 1 to the child with a picture of one candy beside it and 2 with a picture of two candies beside it. Practice number recognition in a fashion similar to alphabet recognition, by making picture cards with the number and correspondingly that many candies/ balls etc.

Give your child practical exposure with coins or pebbles for counting. Once counting till 10 is achieved start with simple additions and subtraction exercises. Practical examples with real objects like biscuits or chocolates are often better understood by them.

Your child also needs to loudly vocalize the number being practiced because mind calculations are not easy for him. Reinforce child's every positive attempt.

b) Color and shape recognition

You could start with one color and one shape at a time. Basic colors like red, yellow,

green, white, black, blue and shapes like circle, triangle, square, star, rectangle need to be worked upon.

Use real objects to teach the concept of shapes. For example, ball for circle / round, a book for rectangle etc.

Incorporate objects of similar colors in the child's daily routine so that he gets to see it frequently and starts recognizing fast. For example red colored school bag, water bottle, apple, T-shirt etc.

Putting up charts in the room will also facilitate faster recognition. A lot of language stimulation is necessary so that child tries to imitate and say the words.

Matching exercise like matching the red color to an apple or black color to your hair etc. need to be practiced. This will increase the child's vocabulary and also he will learn to describe object better. Use songs or rhymes to teach such associations (For example- 'the grass is green and the rose is red...'). Don't forget to reinforce your child's positive as well as negative responses to facilitate his/her development.

c) Observation skills and picture description:

This skill is practiced only after the child develops a vocabulary comprising of nouns, adjectives, verbs, and prepositions.

Show a picture to your child or place a few known objects known in front of him and ask him to name all the objects. Now, request him to pick up a particular object and describe it. For example if your child is having an apple in his hand, ask him to name it. Initially give him alternatives or suggestion. For example, "what do you have in your hand? Is it an orange or apple? Yes. You are right. It is an apple. What is an apple? Is it a fruit or a vegetable? It is a fruit. What color is it? Yes, it is red in color". In this way the child's observation will improve.

Slowly, progress to more complex pictures. For example, show your child the picture of a zoo or a supermarket and ask him to name all the small and big things he can observe in the picture. Initially, do not time the task. As the child starts perfecting the activity, you may begin to set time limits or use a count of the number of errors to improve his efficiency and accuracy. Reinforcing is very important to improve accuracy and perfection.

d) Thinking and reasoning skills

This is the highest level of cognition requiring maximal application of all skills. The child has to learn to associate between similar objects and identify differences between dissimilar objects. For example, you may progress in complexity by asking your child to name five fruits, followed by five yellow fruits and five animals that live in water etc. Also, you may request him to enlist ten uses of water or the various modes of transport etc.

Once the above is achieved, you could start working on abstract concepts like "greater than", "lesser than" etc. Use practical demonstrations and pictures to teach

him. Matching and sorting daily objects into baskets based on their use or colors or size can be practiced. Encourage your child to help you out in daily tasks such as folding clothes and separating shirts from pants, placing fruits and vegetables in their appropriate shelves in the refrigerator etc.

Mind mapping could be practiced to facilitate faster learning and generalization. A word is given to the child (for example, sun) in center of the chart with 5 arrows arising from it. Here the child has to fill in words associated to 'sun' like, solar energy, heat, plants need sun, sun is required for life etc. Again 5 words related to 'life' could be filled out by him (like oxygen, food, water etc.) This will improve the association formations, reasoning and vocabulary. This can also be used to improving the memory and retention.

The above section delineates some strategies and activities that may be used by you at home or at school to improve the child's comprehension, communication, social skills and cognition. With problems in autism being specific and unique to each child, it is best to consult a qualified Speech and Language Pathologist for appropriate and individualized management strategies.

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19.2 How Can You Improve / Facilitate Non-verbal Communication?

A) Eye contact :

Visual (sight) and auditory (sound) stimuli can be used to improve eye contact. Move flickering lights in front of the child's eyes & demonstrate how he could track the light with his eyes. Reinforce this behavior by giving the child things he likes in small quantity. Regular practice is necessary to increase the duration of eye contact. For example, ask the child to track a light/ sound stimulus (torch, bell, mobile phone etc.) from top to bottom or even from left to right side. Place an eatable or candy at the end point. If your child wants to eat, he must track the light/ sound stimulus from top to bottom.

Hold some glittering object near your eyes and encourage child to look in your eyes. While being fed make it compulsory for your child to look into your [parent or caregivers] eyes.

Every child has some favorite or most desired item that can be used as a reinforcer to improve eye contact. For example, if you child loves to play with a soft toy, then make him look into your eyes when you give that toy to him. If he doesn't make eye contact, he does not get the toy. For this, the child will need practical demonstration where he will first observe what he needs to do and then imitate you. Only verbal requests/ commands may not be understood. The important thing is to hand out the toy or praise your child by clapping or awarding a star immediately after he gives you eye contact. Do not ask him to do it once again before providing the reinforcer.

B) Recognition and use of facial expressions :

Often these children do not understand facial expressions like a happy face, sad face, angry face etc. Improving recognition of this type of communication is very important.

Posters/pictures cards demonstrating all these facial expressions along with associated situations leading to such expressions can be useful. For example, receiving a chocolate and a happy (smiling) face beside it. Similarly, not receiving chocolate beside a sad face, breaking a vase beside an angry face etc.

Now when you show these cards to the child, imitate those expressions along with verbal explanations. This will give the child visual as well as auditory stimulation. Carry out this task every time a particular expression is required of him/her.

Click a picture of your child whenever he / she gives an expression and associate it with a particular situation. Replace the picture cards with these pictures of your

child. Try to make it as realistic as possible because children do not understand abstract things.

Once the child understands the associations, show him the pictures and ask him to match with the correct situation and vice versa. To achieve this it will take regular and long term practice.

This way the child will learn to understand facial expressions and changes in tone. Use reinforcers to encourage the use of adequate gestures while communicating.

C) Body gestures and posture :

Children with autism fail to give adequate gestures required to assist communication like waving goodbye, handshake, giving a hug etc.

Every time your child meets a person, encourage him to shake hands and say "hello". When he does that, appreciate his behavior with adequate reinforcement. For example, give a sticker, star, chocolate etc.

Give him/her a hug whenever he does something good or puts up a good behavior. Similarly encourage him to wave good-bye when somebody takes a leave. These body gestures are very important which child has to learn.

Multi sensory stimulation facilitates communication. Like showing a picture, demonstrating to the child how to wave "goodbye", letting the child listen to the tone, feel the inflation in voice and observe the facial expressions will help the child imitate. Video recording these gestures and playing it repeatedly for the child will provide good feedback.

Similarly you could do a matching of picture cards with your child. This will improve his recognition of the body gestures.

Each time somebody meets the child or departs, encourage him to practice the gestures. Role-playing with the child's favorite soft toy can be interesting. In a hypothetical story like situation, you may enact out gestures, postures, expressions etc. with the toy. This will be easy for the child to imitate, learn and incorporate in pretend play with his toys.

Again, click a picture of the child expressing the required gestures or behaviors while playing with a soft toy. Show him the photograph to motivate him to do the same with you or other people. Use appropriate reinforcers.

D) Head turn response to a name call :

Children with autism often do not respond when their names are called out. The fact that every individual or thing has a name by which they are identified is not understood by them. They have difficulty in relating themselves to the world around them. Primarily, it is important to develop self-recognition (concept and understanding of themselves and their identity) in them.

Lay out several photographs of their own in front of them. Let the child identify his/her photo from a bunch of random photographs. Ask them to point at the photograph and then to self, each time.

Similarly, teach them to recognize you in the photographs. Ask them to match the person in the photographs to the actual person i.e. you as a mother or father. This can then be extended to other family members, thus improving self-recognition, visual image and associations.

Once child learns to recognize visually, shifting to the auditory (name call) mode is easy. For example, if your child's name is Amit, ask him "Can you find Amit's photo for me? Where is Amit in these photographs? Yes that's right. This is Amit (pointing at the photograph and then at him)."

Now you may try playing a game with your child. Ask him to guess and identify the source of a sound. For example, the whistle of a pressure cooker was heard from the kitchen, the telephone ring is being heard from the bedroom etc. You could do the similar exercise by asking him to follow your voice or name calling, with his eyes closed. With this, head turning in response to name call will improve. Similarly, the child will learn to respond to your voice. Again adequate reinforcement is necessary.

E) Attention and concentration :

Autistic children are reported to have poor attention and concentration. This affects their performance of daily activities and learning. Hence activities to improve these needs to be planned while keeping in mind the child's interests.

Coloring or scribbling activities, joining dots, pattern drawing etc. can be attempted.

Thumb painting, finger painting, painting using different shapes like lady's finger dipped in color and stamps, sponges of different shapes can also be used.

Paper folding activities, Origami can be helpful. Give your child paper to make small bits or paper balls by tearing it and then putting them into a box. Later, ask him to glue the paper pieces and paste on a chart paper to make a collage design. Color papers, use of sparkles etc can make the activities interesting. Encourage and appreciate creativity.

Water Activity: Swimming can be introduced because children love to play with water. Hence this can help improving attention and concentration. Similarly ask child to carry out few tasks while inside water. For example, let your child wash small clothes in water by observing you in sequence. This will improve attention span, observation skills, imitation skills, sequencing and command following.

Apart from this, let the child carry out other routine tasks requiring water like washing fruits, vegetables, preparing the pressure cooker for rice, wiping table with wet cloth, watering plants etc.

Music: Most children with autism have an affinity towards music. Giving them drums to beat, a piano to play tunes or a mouth organ to blow and make different

sounds can be beneficial. Using a microphone and speaker to amplify and replay what the child sings or hums can make him attentive. Encourage your child to follow tunes, rhythms, beats etc.

Dance: Jumping around, spinning around or swinging is enjoyed by most of these children. Dance can be used to provide them the movements and sensations that they seek, to improve their imitation, attention and concentration, gross motor (hand and leg) co-ordination, body awareness and balance. Simple steps to musical beats in front of a mirror, is effective.

Sand Activity: Here make child play in a sand-pit (wet/free flowing). Encourage him to build castles, forts, draw on sand (eg, face, standing line, sleeping line etc.). Sand painting can also be done as an activity which this improves eye hand\ coordination and attention span as well.

Cycling, skating, and outdoor games like basketball, football, Volleyball: These activities utilize energy in a positive way to improve attention, concentration, balance, body awareness, tone and help reduce hyperactivity. All these activities can be combined with or used as reinforcers, when required.

Writing Activity: This activity involves teaching child to draw lines, join dots, and then learn to write alphabets and numbers. Initial stage would be just copying alphabets and numbers. Once the child learns the writing skills, help the child to write alphabets and numbers with support. Last stage would be writing independently by just listening.



Figure 19.12(1) : Colouring within borders



Figure 19.12(2): Writing

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19.3 Using Picture Exchange Communication System [PECS]

This is a very structured method of using pictures to enhance communication. Children with nonverbal autism need some mode of communication. Often children with autism express their needs by pointing out towards the desired objects or dragging their parents to the area of interest. In situations when these strategies do not work or are not feasible, what alternative do they have? They may start screaming, getting restless and get frustrated. It's not always possible for parents to understand what their child wants. Here, if the child has an option to select his desired item from a set of pictures, then it would be easy for you to understand your child's needs and automatically your child's frustration will be reduced.

PECS should be used systematically as indicated by a speech therapist. There is evidence that PECS is easily learned by most children, with its primary benefit being a means for communication by children and adults who have little or no speech due to autism or other developmental disabilities. It is very important to note when to start with PECS and identify those who are good candidates for this communication system. Since many people on the autism spectrum tend to learn visually, it makes good sense to communicate with images. Just as important, images are a universal means of communication and they are just as understandable by strangers or young peers as by parents or therapists.

PECS is based on the ability of children with autism to understand, comprehend, remember and think visually. While many children with autism are visual learners and think in pictures; a few others may be taught using songs. If your child learns songs easily, use the strength to enhance his/ her language skills. Incorporate new words into a song.

Who is an ideal candidate for PECS training?

- PECS training is not limited by age but rather by a small set of criteria. Firstly, the candidate for PECS training should be an intentional communicator. This means that the child (or adult) is aware of the need to communicate his/her message to someone, even if it is in a limited fashion. The child (or adult) who drags someone across the room to the location of an object that he or she wishes to have, has at least an initial notion of intentionality. The child (or adult) who attempts to obtain things without visually checking for an adult or involving him or her in some fashion in the quest to fulfill a desire or need, may not be intentional and may need a different approach before PECS training.
- Secondly, your child should have some individual preferences, in addition to having intentionality. If one has no or weak preferences, then it may be difficult to understand and learn to communicate via the PECS approach. It may be appropriate to help your child develop a repertoire of likes and dislikes through

trial and error or through a history of exposure to various types of food, objects, or activities.

- Picture discrimination ability is not a pre-requisite criterion. Those who do have discrimination skills, may make faster progress in the initial stages of the program. Some individuals may spontaneously demonstrate that they not only have the ability to discriminate pictured information but that they also know how to use pictures to communicate. These individuals might be locating and bringing pictures or catalogues on their own to parents or teachers in order to indicate their desires.
- Although the PECS strategy is primarily used with individuals who are nonverbal, it could be used with individuals who are echolalic, those who have unintelligible speech, and those who have only a small repertoire of meaningful words or signs in their repertoire. Careful consideration of the program and its strengths and weaknesses should play an important role in program selection for each child with communication deficits.
- There is a debate about the disadvantages of PECS. Some people believe that if it is introduced then child would never attempt to speak, whereas others believe that this assumption is a myth.

How do you go about with the PECS approach?

Their training program prepares you to work with a child through six phases:

- **In Phase one**, the trainer (that's you) works with the child and the caregivers to figure out what might be most motivating to that individual child (a ball, toy, food, etc.). Cards are created with pictures of the motivating item. A parent and the facilitator help the child discover that, by handing over the card, he/ she can get the desired object.
- **In Phase two**, you move farther away from the child, so that the child would actually need to come over to you and hand over the card. This is a life skill lesson in seeking and obtaining another person's attention.
- **Phase three** requires the child to discriminate among multiple pictures when requesting an item. For some children this is easy, for others it may be difficult. Some children learn best with photos, and others with graphic images that approximate the appearance of an object.
- **Phase four** starts with the process of building sentences through "sentence strips." Instead of a single picture they may drop an "I want" starter on the strip to create the sentence: "I want ball."
- **Phase five** challenges the child to build questions using sentence strips, starters and pictures.
- **In Phase six**, the child is taught to comment on the world around him/ her by responding to questions such as "what do you hear?", "what do you see?" etc.

They learn to use descriptors ("the big green ball") and more complex pictorial language.

This learning process may take weeks, months or years to complete. Throughout, the child is encouraged to use PECS in various different settings and with different partners. This way child's dependency can be reduced and communication can be enhanced. When used along with Speech Language Pathologist's guidance/ supervision then child can be taught to initiate communication for his needs. PECS are like visual crutches for communication. Progression from photographs to drawings to words must be done gradually.

What picture cards should you use?

Pictures for PECS should be custom made as per child's requirement. They can be made at home as well. The pictures used with the program may be photographs, colored or black and white line drawings, or even tangible symbols. Selection of picture representation type and size is dependent on individual needs.

The role of a speech therapist is not just limited to development of language skills. They employ a holistic approach for developing communication skills (both verbal and non verbal), cognition and social skills. "Remember, the aim is effective communication and not speaking".

		
I want	I see	thank you
 drink	 biscuit	 apple
 cake	 crisps	 banana
 book	 sand	 bricks
 pens	 farm	 puzzle
 shoe	 jumper	 trousers
 coat	 sock	 hat

Figure 19.3(1): A PECS Chart

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20. Physiotherapy in Autism

20.1 Current Physiotherapy Approach

What role does physiotherapy play in the treatment of Autism?

Traditionally 'Autism' is presumed to be a triad of behavioral, sensory and perceptual abnormalities. As soon as a diagnosis of ASD is confirmed the parents are advised to consult a range of rehabilitation professionals like occupational therapist, speech therapist, psychologists and special educators. However management of 'ASD' should not be limited to these. Slowly as the understanding of the disease is growing various studies have identified motor and physical impairment. But in the presence of gross behavioral and sensory manifestations the motor symptoms are often overlooked. Physiotherapist can help in optimal development of motor skills and develop program to address any underlying weakness in both sensory and muscular systems in children with autism. This empowers them to interact better with people and encourage participation which improves child's social skills and quality of life.

What causes motor impairments in ASD?

Although sensory processing deficiencies and behavioral abnormalities are profound in ASD, various motor abnormalities have been identified by various researchers in the last decade [2, 3, 4]. Movement initiated in response to internal or external sensory stimulation requires integration of multiple sensory inputs and organization of the responsive motor outputs. Neuroimaging studies have suggested neural connectivity deficits in ASD [5], which may contribute to the deficits in the integration and organization of various neuronal responses. ASD shows less activation in cerebellum with relatively more activation in the fronto-striatal region [Mostofsky, 2009]. Evidence also now suggests that aspects of cerebral morphology are different in people with ASD, both volumetric (i.e., cortical thickness, regional area) and geometric (i.e., cortical shape) features [Levitt, 2003 & Wu Nordahl, 2007]. Different morphological features may have varied neuropathological and genetic underpinnings [Panizzon 2009].

What are the motor and musculoskeletal impairments in ASD?

Movement is an integral part of our social, emotional, and physical lives. A four month old baby excitedly kicks her arms and legs in response to any pleasant stimulus or a 7-8 months old toddler will crawl to retrieve her favorite toy, shake it to hear the sound it makes. As the child grows the length and complexity of movement sequences becomes more sophisticated and planned. But unfortunately children with ASD often cannot coordinate the myriad of movements needed to complete these interactions.

Shetreat-Klein et al 2012 [6], studied the motor abnormalities in children with ASDs. The findings were synonymous with the early findings [2,7,8] showing gait deviations in children with ASDs as compared to their age matched non-ASD peers. Using retrospective video analysis, Esposito et al 2011 showed that ASD group had differences in gait pattern, i.e., postural asymmetry; atypical foot movement, arm movement, and generalized movement. Earlier reports suggested a "parkinsonian gait," characterized by longer stance duration, shorter stride lengths, lack of a heel-toe pattern, and reduced upper-limb movement [Vilensky, 1981]. In contrast, recent reports identified features of "ataxic gait," characterized by instability and imbalance [Hallett, 1993]. In addition they also identified a delay of 1.6 months in achieving the motor milestone of walking. There are problems with running speed and agility, motor planning, bilateral coordination, visual motor coordination, limb strength, static and dynamic balance [9]. One in every five children suffering from ASD is found to have generalized hypermobility of the joints and low muscle tone [10]. Contrary to the earlier views that children with ASDs have normal motor development and performance, various researchers have observed deficits in motor co-ordination [11], postural stability [12], motor planning and performance [13].

Interestingly, children with ASD have difficulty with communication as well as difficulty using motor activity (e.g., gestures and imitation) as forms of communication to support social interaction. Motor imitation has been identified as a significant impairment in previous literature on individuals with ASD, particularly in relation to social communication. Stone et al 1997 suggested that imitation impairments in children with ASD are due to a delay in acquiring imitation skills, rather than disordered sequencing.

Postural control requires a level of stability necessary prior to executing additional motor skills or activities. Without this control, motor activity may be limited to more static positions. Individuals with autism tend to have decreased postural control [Minshew, 2004 & Schmitz, 2003], particularly in circumstances where there is sensory conflict. Children with ASD demonstrated increased sway, abnormal weight distribution, and the absence of typical ankle strategies in standing. A "paradoxical stress response" was noted, indicated by an increase in postural stability in stressful conditions (defined as removal of vision) [Kohen-Raz, 1992].

It is important to understand that motor impairments can lead to great difficulty in fine motor skills like writing, tying shoe lace or buttoning. Motor deficits in these children may be detected late in their lives or may go undetected. Researchers have stressed on

early detection and intervention of these impairments. The table below will help you to identify these symptoms in young children with ASD and offer prompt intervention.

How to identify the motor and musculoskeletal manifestations in children with ASD?

Motor impairments	In adolescent children	In infants and toddlers
Gross motor impairment	Poor eye hand co-ordination, inability catch ball, throw ball, avoid obstacles, climb alternate steps and slowness in complex physical activities	Delayed milestones, timely milestones but poor quality of movement and delayed onset of walking
Fine motor co-ordination	Difficulty in buttoning shirt, tying shoe laces, switch on the lights, poor handwriting, inability to color within the lines	Delayed reaching and grasping activities
Stereotypical motor mannerisms	Stereotypical and repetitive behavior is very common	Uncommon in young children, occasional excessive hand banging may be present
Postural deviations	Slouched posture, when standing erect bulging the chest forward, inability to maintain erect posture while sitting, frequent complains of neck pain or pain between the scapulae	Poor posture in activities like rolling and sitting
Muscle weakness and tightness and muscle tone abnormalities	Excessive prominence of shoulder blades, Over straightening of knees and elbows, flat feet, Reluctance to lift heavy objects and Easy fatigability	Delayed milestones, slowness of movement, inability to carry out motor tasks like other toddler

What to expect during a physiotherapy evaluation?

During physiotherapy evaluation a child's neuromuscular and musculoskeletal systems are assessed. Observation is the key in the assessment of children with ASD and therefore physiotherapist may need to assess the child over multiple sessions to identify the motor impairments. The therapist closely looks at child's ability to take in sensory input and control motor output. They assess the facilitating and limiting factors for different gross motor skills like walking, jumping and running, stair climbing, and

kicking a ball. Through play, the therapist will observe how a child uses his balance reactions and protective reactions. How the child plans motor skills and strategizes to move in and out of different positions. The therapist will also observe the child's posture in a variety of positions, and how the child's posture affects breath control, oral motor control, and vocalizations. In addition a routine examination of muscle strength, muscle length and range of motion will be undertaken, which will require the child to perform various physical activities and tasks.

How will a therapist plan the sessions?

- On the basis of evaluation, the frequency of the sessions (everyday, alternate day or twice in a week) and child's therapy sessions are planned. Children with predominant motor and sensory deficits may initially need session's every day. Children with who are only found to have issues like poor coordination and coordination may need session twice/thrice a week. Home program is very essential, as these exercises need a lot of repetitions. So parental education is a must.
- Proper planning is very essential before initiating therapy session .The key things to remember before planning a session is to make sure it is fun, achievable for the child, not too easy and variety of activities are included.
- As we all know children with ASD have difficulty in communication. It is advisable to use more visual clues than verbal instructions. Use of picture cards or mirror to demonstrate the movement may be needed.
- Therapy session could be divided into three parts. First 10 minutes of the session to be utilized for planning according to child's mood and orientation. Next 30 minutes to give exercises like muscular strengthening, coordination and balance exercises and stretching. Next 10 minutes should be used to calm the child either by using any play therapy or parental counseling.
- In addition to active physiotherapy session an aerobic endurance activity like walking, running, jogging, cycling, jumping, bouncing and dancing should be incorporated and performed for 20 - 30 min / 3 -5 times a week.
- Various strategies could be used to teach and execute these activities to children with ASD. Parent / caregiver involvement in the exercise is very important. Demonstration of a particular activity/movement by parent/ caregiver; using visual and auditory to cues to perform the activities are some of the strategies that physiotherapists could adopt.

Strategies used in executing the therapy session - use parents or care givers to teach the movement (with photos)



What are the potential benefits of physiotherapy for children with ASD?

Although several motor impairments have been identified; the patterns, sources and the causality remains poorly understood. It was believed that the motor symptoms could be corrected when the sensory and perceptual deficits are addressed; but it is intriguing to see the effect of physical intervention on various symptoms in ASD. Oriel et al. 2011 found that 15 minutes training with aerobic activity in children with ASD significantly increases the performance in the classroom task [16]. Physical intervention through aerobic activities and strength training reduces the self stimulatory behavior [17], repetitive motor behaviors [18,19], improved social behavior and classroom performance [20]. In the view of these benefits of physical intervention, physiotherapy has been integrated in the clinical framework for treating children with autism [21].

Physiotherapy helps to improve postural control to increase stability during fine motor, gross motor, and self-care activities. Improve static balance to improve motor control and attention and decrease impulsivity. Learn to perform the ideation, sequencing, timing and execution components of motor planning. Maximize sensory processing and organization skills to put into controlled motor skills. Lay down the foundations of gross motor skills to support participation in community and peer activities. Most importantly physical exercise has a calming and relaxing effect.

Recently different treatment modalities like aquatic therapy have also been used by physiotherapist for the treatment of ASD. Aquatic therapy helps to improve body awareness, coordination, muscle tone, and to reduce tactile hypersensitivity; it also provides vestibular stimulation and is therefore being explored widely.

To conclude, children of all ages learn through movement and need to master core motor skills in order to maximize their overall potential. Beginning as infants they develop stability so that they can learn to use their hands and feet independently from the rest of the body. They also learn how to manipulate the environment and how to move their bodies within it. They use movement to bond and communicate with others and to explore the world. Limitations in motor skills can lead to difficulty with all areas of development. Physiotherapy can be a beneficial part of a team approach to help children with ASD to be successful and independent as much as possible in school, home and in the community.

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20.2 Aquatic Therapy for Autism Spectrum Disorders

Imagine living in an environment with constant loud noise and bright lights, where you can't feel, taste, see or hear properly but everyone around you is able to do that just fine. If the movements in your surroundings are too scary like you are in a roller coaster or too little like you are in a swimming pool and struggling to find hard ground and to make it worse you can't communicate with anybody around you in a manner they can understand; how will you feel? Terrified, frustrated, agitated, scared, anxious may be a lot more than that. This is the horror a child with autism faces every single day of his life. It is a difficult life for them; tasks that we take for granted like eating, bathing, brushing, combing are fraught with unpleasant stimuli. Communication is difficult. Receiving and expressing affection is difficult. Something as enjoyable as playtime could also mean anxiety for them.

Autism is one of the neurodevelopmental disorders with unknown cause, un-understood symptoms and therefore inadequate treatment strategies. This chapter will state to you why should your child undergo aquatic therapy? It will state the health benefits of aquatic therapy and what to expect in an aquatic therapy session.

What is aquatic therapy?

The Aquatic Therapy and Rehabilitation Institute defines Aquatic Therapy as "The use of water and specifically designed activity by qualified personnel to aid in the restoration, extension, maintenance and quality of function for persons with acute, transient, or chronic disabilities, syndromes or diseases".

Simply put, aquatic therapy means making use of various physical and chemical properties of water for the treatment of various disorders.

The most common question that arises in the mind is when we live on land how can being in water help us. That is also the answer to the question because water provides us an alternative environment where the body is more supported and can experience a larger degree of freedom otherwise unavailable on land. Aquatic therapy is always used in conjunction with land based rehabilitation.

Aquatic environment is safe and easy to maintain however it also has an inherent risk of drowning and therefore the therapy must be undertaken by a trained and qualified professional.

Aquatic therapy may consist of individual sessions with therapist and the child, it may also consists of sessions where the family members or care takers are involved or the sessions may also be conducted as group therapy with multiple children and their parents or care takers.

Various techniques are used in aquatic therapy. Some of the most commonly used techniques are Halliwick, Bad Ragaz ring method, Watsu, Aai Chi and aquatic exercises.

Why aquatic therapy?

The most important is to understand the benefits provided by aquatic therapy and even simple immersion in water. But before reading about these let's first take a look at what are the difficulties experienced by these children.

Children with autism face range of difficulties and exhibit varied symptoms. Various sensory, motor and cognitive systems are impaired. Children find it particularly challenging to communicate, express, reciprocate socially and integrate the sensory inputs. Till very recently the motor impairments of these were underestimated but in last decade various motor impairments have also been identified.

Behavioral abnormalities start with some of the earliest symptoms being inability to establish or maintain eye contact, lack of interest in forming peer relationships and inability to modulate the emotional responses leading to aggressive behavior or self injurious behavior. Some children seek sameness and may get upset with even slightest change in routine. They lack the language and communication skills. They also show sensory processing abnormalities. The inputs we receive from the environment through all our senses are crucial in forming our motor, sensory and cognitive responses and in turn our social behavior. Children with autism may show hyper-responsiveness to these inputs or hypo-responsiveness or sometimes a combination of both to different sensory inputs. Hyper responsiveness in turn leads to anxiety, aggression, stereotypical behaviors or repetitive behaviors. Sometime these children may seek more sensory inputs most often they seek deep pressure and vestibular inputs. These sensory processing and integration impairments may lead to lack of normal motor response by the motor systems. The children with autism may also exhibit hypermobility of joints, hypotonia, postural deviations, in-coordination, poor balance and poor fine motor control.

Aquatic therapy helps in improving all of these symptoms. Aquatic activities are a fun and enjoyable experience that have many physical, psycho social, cognitive, and recreational benefits. Water activities provide autistic children with proprioceptive and tactile input. Children with Autism have significant sensory difficulties, and are very distractible. These children over or under react to stimuli in their environment and have very strong reactions to certain textures.

Beneficial effects of water immersion:

Mere immersion in water provides multitude of physiological benefits (1).

Compressibility of water is poor; therefore it exerts a pressure on the immersed body from all the directions. This compressive force helps pump the blood from blood vessels back to the heart, increasing the amount of blood that enters the heart. Due to this increase in the volume of received blood heart is able to pump out more blood with every heart beat; increasing the cardiac output (2).

Shoulder or Neck deep immersion increases the cardiac output and also created a larger pressure gradient in the blood pumped out and the blood vessels of brain, thereby

increasing the blood supply to the brain. Increased blood supply means that brain receives nutrients much more efficiently and the toxic waste is taken away quickly. Water immersion therefore has a beneficial effect for memory and cognitive tasks (3).

Inappropriate or exaggerated responses of anxiety to any unpleasant stimuli in children with Autism spectrum disorders are thought to be due to autonomic nervous system dysfunction causing over arousal of sympathetic nervous system and depression of parasympathetic nervous system (4). Altered autonomic nervous system function is thought to be one of causal factors in Autism Spectrum disorders (5). Increased blood supply to brain and cardiac systems also leads to activation of the parasympathetic nervous system and suppression of the sympathetic nervous system; after immersion in water (6). Mere immersion in water therefore helps reduce anxiety, hyperactivity, repetitive motor mannerisms, stereotypical behavioral and inappropriate emotional responses (7). Water immersion results in calming of the children on spectrum.

Buoyancy and upthrust experienced in water provides freedom of movement, which is lacking on land due to poor motor planning and co-ordination and increased risk of fall. Water supports the child but at the same time creates a relatively unstable environment providing vestibular inputs. Viscosity of water combined with hydrostatic pressure provides proprioceptive inputs. These are crucial in addressing the low tone and in-ordination in these children.

Why not just immersion in water?

Although immersion in water has these beneficial effects these could be amplified if used as therapeutically. Therefore, it is important that a child on the spectrum is made to do activities in water with varied levels of immersion. Children may be sensitive to water splashing on their face and may not like it; in such cases a professional supervision is required. As the sessions progress children adapt to water (8) but this sensitization has to be carefully planned and executed gradually. Children may over rely on the visual inputs when proprioceptive and vestibular sensory processing issues exist. Water limits visual cues and therefore prior arrangements for visual or verbal or tactile cuing are required. Very commonly picture cards are used for cuing while treating these children, in a water environment therapist will also make use such laminated cards to stimulate children for performing various activities. A therapist while planning the aquatic therapy session takes into consideration limitations of the child and makes use of his or her strengths.

Session based therapies are known to provide following benefits :

1. Improve Posture, Coordination, and Body Control: Because water reduces a child's body weight by 90% while also adding resistance, many therapists report improvement in muscle strength, balance, and coordination (7-11).
2. Improve Sensory Issues: Children with autism tend to over or under react to stimuli in their environment, including light and touch. The warm water and hydrostatic pressure of aquatic therapy help soothe the child in a safe and supportive setting.

As a result, many therapists report an improvement in the child's ability to tolerate touch following aquatic therapy (7-11).

3. Improve Social Skills: Group aquatic therapy has often been used to help in social skill training, promoting engagement and cooperation amongst children. As a result, many therapists note significant improvements in eye contact and self-confidence amongst children (7-11).
4. Improve Cognitive Functions: Aquatic therapy has been known to help improve a child's attention span, concentration, impulse control, frustration tolerance and ability to follow instructions (7-11).

What to expect in a session of aquatic therapy?

An aquatic therapy session can be conducted as an individual session or group therapy session. Group therapy sessions are particularly beneficial for improving the social skills and behavioral abnormalities in these children.

A detailed assessment should be duly undertaken before the session. Building a rapport with the child on land before entering into the alien water environment is essential. There are various techniques that a therapist may utilize during these sessions. Some of the common concepts in aquatic therapy are Halliwick therapy which uses a 10 point program to increase the water adaptability, breath control and movement of the body when immersed in water. Bad Ragaz ring method is essentially used for motor system deficits like low tone, muscle weakness and in-coordination. Aai chi uses various postures and movements in water which provide active relaxation whereas Watsu is a technique used for passive relaxation while in water. Various aquatic exercises can be used for building the aerobic endurance. Aquatic therapist will make use of all of these techniques in combination for optimum results.

The time duration for the aquatic program is pre-determined. Ideally an aquatic therapy program for ASD should be for about 2-6 months with a frequency of 1-3 times per week.

What does the evidence suggest about aquatic therapy?

The current evidence for benefits of aquatic therapy in Autism is preliminary and limited. The early evidence comes from a case report of a 9 year old child suffering from Autism treated with a 10 week long aquatic therapy program primarily based on Halliwick concept which showed improvement in physical fitness parameters like balance, speed, agility, cardiorespiratory endurance and muscle strength, endurance and power. It also showed reduction of repeated stereotype motor mannerisms. This was followed by a survey of the perception of Occupational therapists about the benefits of aquatic therapy in Autism. Eighteen therapists participated in this study and unanimously agreed that there is significant improvement in tolerating touch and maintaining eye contact post therapy. When further tested with non randomized controlled trials they too showed similar results. Four non randomized controlled trials unanimously showed beneficial

effects of aquatic exercises over normal treatment methods in aquatic skills and safety, cardiovascular endurance (Ability to perform activities in the target heart rate zone for a longer time), muscular strength and endurance and social skills. One of the trials showed reduction in antisocial behaviour and repeated motor mannerisms; the other showed increased functional mobility of children and greater satisfaction of the parents with use of aquatic exercises.

The available evidence is therefore clinically significant in identifying the benefits of aquatic therapy in autism to improve motor skills, social and behavioural skills and physical fitness. The strongpoint of all these trials was use of relevant and standardized outcome measures. However, the results cannot be generalized over the spectrum as participants in all of the above mentioned trials were small in numbers, categorized as high functioning autism or Asperger's syndrome between the age group of 4 to 12. The long term carry over effect of the therapy has not been tested. The exercise programs lasted for a maximum of 14 weeks and a carryover effect was also measured for the same duration. Therefore there is a need to design and conduct trials with rigorous methodologies, that will help explore the effects of aquatic therapy over the complete spectrum of autistic disorders, in children as well as adults and establish clinical as well as statistical significance.

In summary, as discussed, the versatility of water allows for a large variety of goals that can be achieved with children on the spectrum. The distinctive characteristics of this condition have to be considered when designing and implementing an aquatic therapy program for this population. It is important to test the skills on land pre and post intervention, to document the clinically relevant changes.

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21. Diet And Nutrition

Often the nutritional status in children with autism remains compromised. This is mainly because of their inability to swallow and digest many foods. Many of them have food preferences due to their sensory problems, which causes a deficit in the intake of nutrients. An alteration in the diet with respect to the nutritional requirement after assessing the other aspects like the swallowing and digestive ability is necessary so as to improve the quality life of the patient.

Common Gastrointestinal symptoms in autism:

The common physical symptoms of children with autism often include diarrhea, constipation, bloating and gastrointestinal (GI) pain, frequent infections, sleeping challenges and inflammation/pain. For many children with autism, when things go awry in the "gut," negative behavioral changes and cognitive problems occur or are exacerbated. For many, food intolerances, imbalanced biochemistry and digestive problems are at the core of these symptoms. These weaknesses in physiological functioning can be directly tied to biochemical processes that are affected by diet—the absence of required nutrients and/or the presence of offending substances. For many children, altering food choices and adding supplementation affects these processes, promotes healing and can improve autism symptoms.

Every human body reacts differently to different food substances. Understanding that gut and brain are connected helps explain why autism symptoms and overall health can be improved through a diet that supports digestion/GI health and biochemistry. Hence it is essential to follow a diet prescribed specifically by a qualified Nutritionist. This prescription will be based on all the information gathered about the child. The nutritionist notes down the following points:

- Age, height, weight, body mass index (BMI)
- How many times does the child eat in a day
- Brief description of all meals
- Diet plans followed previously and the time span

- Allergy to any foods
- Foods that cause stomach discomfort
- Addiction to any particular food
- Aversion to or inability to eat any consistency of food
- Amount of water intake per day
- Activity levels
- Constipation or loose stools
- Favorite foods and foods disliked
- Table manners
- Any medical food tolerance tests conducted

A detailed diet plan, keeping in mind the current habits of the child must be charted out.

What are the common nutritional deficiencies seen in autism?

- Beta-Carotene found in plants and is converted into Vitamin A in the body. This Vitamin helps in cell growth of tissues in the brain and stomach lining, which is deficient in children with autism. The sources of this nutrient are sweet potatoes, carrots, red and yellow capsicums, pumpkins, muskmelons, dark green leafy vegetables, red and yellow colored vegetables and fruits.
- Vitamin B-6 is part of the vitamin B-Complex. It helps in transmitting information to the brain (i.e. conduction of nerve impulses) and is critical for language development, alertness, increasing attention span, eye contact, improved sleep, better speech and coordination of movements. The food sources include green peas, turnips (shalgam), yams (suran), fish (salamon), cashew nuts, peanuts, all whole pulses and sprouts, chicken, etc.
- Vitamin B-12: It is important for the regeneration of red blood cells, promotes growth and prevents loss of vision. It plays a vital role in protein, DNA and RNA synthesis. Low levels of Vitamin B-12 may be due to poor intake of food or poor absorption, leading to anemia. Food sources of vitamin B-12 are milk and milk products, meats, cheese, eggs, fish, etc
- Lack of folic acid during pregnancy is said to be associated with the risk of developing autism. One of the most important functions is that it helps in producing new genetic raw material. Low levels during pregnancy can lead to brain damage in the child. Hence, supplementation started at the first trimester is essential. Sources of folic acid are liver, dark green leafy vegetables and nuts.

What are the causes for these deficiencies?

- Chronic diarrhea/constipation: With diarrhea and constipation being a common

co-morbid problem in autism, the resultant mal-absorption can cause nutritional deficits.

- Gastrointestinal inflammation: Many children with autism, experience chronic gastrointestinal inflammation and structural compromise in the digestive tract. This intestinal inflammation is likely to reduce nutrient absorption.
- Dietary restrictions: One of the classic symptoms seen in autism is the restricted interest in food items, or selective preferences to certain types of foods. Restricted, self-limited diets are likely to be responsible for deficiency in one or more essential nutrients.

Diet recommendations specific to autism :

Given below are some recommendations:

- **A GFCF diet :**

The most specialized diet commonly prescribed for children with autism and proved to be successful is the Gluten free and Casein free diet (GFCF- diet). Studies have found that a gluten-free, casein-free diet was effective in improving ASD behaviors, physiological symptoms and social behaviors in children with GI symptoms and with allergy symptoms compared to those without these symptoms(2).Gluten- and casein-free diets are seen to offer a relatively uncomplicated approach to symptom management compared with some other interventions(3).Some parents hesitate to try autism diets because they don't know if special diets work, why they work or how they work. When parents correctly implement specific autism diets, improvements in gastrointestinal problems (including diarrhea and constipation), language, learning, focus, attention, eye contact, behavior, sleep difficulties, toilet training and skin rashes/ eczema have been observed(1).Experimental studies on the use of a GFD, CFD, or combinatorial GFCF diet for ASCs have suggested an amelioration of symptoms and improved developmental outcome. Gluten and gluten like proteins are found in wheat and other grains, including oats, rye, barley, bulgur, durum, kamut and spelt, and foods made from those grains. They are also found in food starches, semolina, couscous, malt, some vinegars, soy sauce, teriyaki sauce, flavorings, artificial colors and hydrolyzed vegetable proteins.

Casein is a protein found in milk and foods containing milk, such as cheese, cream, butter, yogurt, ice cream, whey and even some brands of margarine. It also may be added to non-milk products such as soy cheese and hot dogs in the form of caseinate.

The GFCF diet mainly eliminates all wheat (and wheat products) and milk (and milk products). Although it may sound difficult, several alternatives are easily available. The Indian diet, for instance, includes a variety of other cereals apart from wheat. Hence such a diet is not impossible.

Eliminating wheat and milk can be a cause of worry. You may wonder how your child would receive the other nutrients like calcium, vitamin B12, etc. However, when the diet is planned it takes care to include other sources which will fulfill the daily RDA (Recommended Dietary Allowances).

A casein-free diet is a plan in which milk protein (casein) is eliminated by avoiding all dairy products and all foods containing casein (for example butter, cheese, yogurt, cream, ice cream, etc.). Foods containing milk or casein in any form should not be purchased. Read labels of purchase food items carefully, because milk or milk products can be present in items like soy, yogurt or sausages. Maintaining a milk-free diet can be hard at first because milk or casein is present in many prepared foods.

A casein-free diet is often, if not always, implemented in combination with a gluten free diet, which calls for the elimination of wheat, barley, rye, oats, and any product made from these grains. Both diets are called elimination diets because a particular type of food is virtually eliminated from the child's meals.

The major health concern for a child on a casein-free diet is whether the child receives adequate nutrition. All children on elimination diets should be under the care of a nutritionist or physician. Also, look for calcium-enriched rice milk, soy milk, and orange juice for easy sources of calcium.

Eggs do not contain gluten or casein. When you prepare your eggs, be mindful of the oils you use. Omelets are a way to pack flavor, nutrition and a full-stomach, all in one. Include fresh chopped onions, fresh mushrooms, salt, and pepper to your omelet. Fresh meat, fresh poultry, and fresh seafood will be gluten and casein free. Be careful though, with prepackaged meats, as they can contain added ingredients. Tofu or soya paneer is a substitute for meat and can be prepared with natural spices.

Fresh vegetables and fresh fruits do not contain gluten or casein. Add a fruit into the daily breakfast such as diced bananas, strawberries. Give your child whole grapes with lunch and fresh potatoes with dinner.

FOODS TO AVOID...

<p>Simple sugars can be very hazardous to those with Autism. This increases the energy levels on a temporary basis which can be attributed to hyperactive behavior intermittently. Sugar substitutes like jaggery can be used which is also rich in iron. Artificial sweeteners must be strictly avoided too.</p>	<p>Avoid big fishes as they are concentrated with toxins from the sea especially mercury, an immunotoxin that can lead to lowering the capacity of the immune system</p>
<p>Artificial colors, flavors or any preservatives must be strictly kept at bay</p>	<p>Toxins like Monosodium Glutamate-MSG (ajinomoto used in Chinese foods) can cause over-excitation in the brain leading to hyperactivity, hence must be avoided.</p>

Remove yeast -containing foods--- Breads, grapes, plums, aged meats and cheeses, and vinegars can feed yeast and should be removed	Prevent the introduction of further toxins into the body by avoiding aluminum and plastic in cooking
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SAY YES TO...

A Rainbow diet: This is a diet consisting of colorful vegetables and fruits, in plenty. Introduce new vegetables and fruits slowly.

The human brain needs lot of antioxidants, phytonutrients, vitamins and minerals to work its best. All the mentioned nutrients are packed in veggies and fruits.

Use of probiotics in food can help soothe the gut and improve its functioning. Probiotics are found in naturally fermented foods like, cheese, idlis, dhoklas, etc. They are easy to digest and can be made colorful and nutritious by adding veggies and sprouted pulses. Children generally love such snacks and they are easily consumed.

Mix rice flour, jowar (sorghum or whole cereal) flour, quinoa (readily available in the market), moong or green gram flour (to be ground) and corn (makkai) flour in equal quantities. Add all dry masalas (spices) like chili powder, turmeric powder, salt, ginger, garlic to it. Mix a few grated vegetables as per choice. Vegetables can be pureed and added too. Plenty of chopped coriander is good as it not only adds color and flavor to the dish but is also a good anti-oxidant. Dilute the mix with water to a batter consistency. Steam to make idlis or prepare pancakes on nonstick pans. Quinoa does not contain gluten and is high in fiber and iron. It can be used extensively to make upmas, khichidi, etc. Foods, such as, ginger and turmeric reduces inflammation and heals the gut

The Basics...

Follow the instructions below to avoid contact with harmful chemicals, micro-organisms, etc.

Wash hands well before eating	Avoid spraying mosquito repellents or body sprays around the patient
Use glass or porcelain cutlery instead of plastic	Keep away from smokers, as far as possible
Avoid canned food, plastic containers, cosmetics etc.	

A Sample Indian Diet Plan for your child

- Early morning after waking up: Drink a glass of warm water.
- Breakfast: Green tea with poha (rice flakes) or any preparation made out of rice. For example, dhoklas, idlis, dosas or moong chilas (made out of split green gram lentils), sprouts chat or mix dal (lentil) dosa, thalipeth (mixed flour pancake). Avoid adding wheat to any of these.
- Mid-Morning: fruits with lime juice or green tea
- Lunch: Salads and veggies in plenty, jowar (whole cereal), nachni (raagi, rye, finger millet), or rice bhakris (pancakes) with dal (lentil) and any pulse or protein foods (chicken or fish), small quantities of rice.
- Evening: green tea, any dry roasted snack like kurmura or roasted chana (roasted pulses), or roasted poha or chiwda (rice flakes), rice dhoklas, mung dhoklas, rice chakkis (homemade). Avoid biscuits as far as possible.
- Mid evening: soups or fruits
- Dinner: Salads and veggies, bhakris (pancakes) with dals or lentils, or any leafy vegetable
- Before bed time: Cut fruits or soya milk.
- Water must be consumed in between the meals to enhance digestion of the food.

A Sample Western Diet Plan for your child

- Breakfast: Gluten-free bagels with soy milk or muesli with casein free milk, eggs
- Mid- morning: Green tea with fruits (berries are recommended)
- Lunch: Chicken, tuna or salmon with sauté vegetables like broccoli, mushrooms, bell peppers, etc. with loads of ginger garlic.
- Mid-evening: Chicken broth or vegetable soups (avoid adding preservatives and soya sauce)
- Dinner: Similar to lunch. Vegetables and fruits are to be included in large amounts.

Biscuits or breads which are made from gluten free flour are recommended.
Avoid plain sugars or cola beverages completely.

Remember that the above plan is only a guideline to follow. It is best to consult a nutritionist as diet plans are individualistic and should be specially designed to cater to the needs of your child.

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22. Yoga Therapy

Bhagwat Gita II -48

Samatvam Yoga Ucchate: Evenness of mind. Balanced state of mind is necessary to look at any situation, may it be success or failure, to keep the mind steady in any situation. To remain in a balanced state of mind is Yoga.

Yoga is increasingly practiced by people all over the world to improve their physical fitness, as a stress reliever, to improve concentration and lastly to enhance the spiritual experience. But, the extrapolation of yoga therapy to the treatment of a myriad of diseases has only surfaced in recent times.

The philosophy of yoga originated some 2000-3000 years ago although, according to Hindu texts its origin can be linked right to the beginning of mankind. It was Saint Patanjali who organized the science of yoga into a systematic practice and is rightly known as The Grammarian of Yoga. So what is Yoga? It is the union of mind and body, of conscious with the subconscious, of Jivatma with the Parmatma. It is a way of life. It is in effect the science of healthy living wherein one attains physical, intellectual, mental and spiritual harmony.

The Science behind Yoga: How does it heal?

Medical practitioners and yoga experts believe (and as proven by research) that Yoga helps to lower the body's stress response by reducing levels of the hormone cortisol. Cortisol is also called stress-hormone as it is produced under response to stress. Yoga also boosts levels of the feel-good brain chemicals like GABA, serotonin, and dopamine, which are responsible for feelings of relaxation and contentedness. These neurotransmitters are the targets of various mood medications like antidepressants and anxiolytic (anti-anxiety) drugs. In addition to suppressing the stress response, yoga is also believed to stimulate the parasympathetic nervous system, which calms us down and restores balance after a major stress event is over. When the parasympathetic nervous system switches on, blood is directed toward endocrine glands, digestive organs, and lymphatic circulation, while the heart rate and blood pressure are lowered. Thus, our bodies can better absorb nutrients from the food we eat, and more effectively

eliminate toxins due to the enhanced circulation. The body enters into a state of restoration and healing.

Researchers have also discovered that yoga improves health in part by reducing inflammation. Patients who practice yoga have significantly improved levels of biomarkers like C-reactive protein (CRP) and interleukin-6 (IL-6). Yoga, thus, balances the body, the hormonal system, and the stress response. It helps to rebalance and heal the body.

Yoga for Autism :

Yoga is an emerging and promising therapy for children with autism. Yoga improves sensory processing and enhances one's sense of personal space, improves gross motor skills and the ability to transition from one activity to another. It helps develops self esteem, improves communication and relationship skills. In contrast to other therapies, Yoga helps these children calm themselves, rather than relying on someone else to provide comfort. After a child has learnt the various poses, breathing practices, and visualizations, he can accomplish this by himself/herself or with a parent.

We have illustrated below some of the simple, yet powerful yoga exercises that help in conditions such as autism. As parents, caregivers and teachers, practicing these, yourself will help you relax and cope with the stress of daily life.

Bhagwat Gita II - 50 :

Yoga KarmashuKaushalam: Do the work skillfully. Skill in work leads to perfection work which leads to excellence. Excellence in work is Yoga.

Patanjali Sutra I - 2 :

Yoga SchittaVrittiNirodha: To control the mental modification of mind and its regulation is Yoga.

1. Pranayama (breathing exercises)

"Prana" means Life and "Ayamá" means control. Thus, Pranayama means control of the inner force of human life. The breath we take in and out is regarded as Prana, which is the bio-energy that endows man with the ultimate potential for self development. It is vital/life force that man must suitably control, channelize and use for the right ends. Yoga prescribes various practices of Pranayama or control of Prana popularly referred to as breath control. The yogic breathing itself becomes a prayer, a satisfying spiritual experience in which one is aware of living in the presence of God.

What are the benefits of Pranayama?

- Better blood circulation
- More oxygenation
- Longevity i.e. full health life

- Mental concentration
- Increase in lung elasticity and capacity
- Purification of blood
- Emotional control
- Cheerfulness
- Prevention of diseases (and cure also)

Life is a series of activities. We conclude one activity only to start another. A preparedness kriya allows a person to be mentally prepared for an activity. Sukhansana is one of the many asana which stabilizes the mind. This asana is named for preparedness or conditioning. Children with autism may not be able to obtain and maintain this posture in which case, it may be performed while lying down. Those who are very hyperactive and restless may not co-operate. In most cases, you may have to repeat performance several times, demonstrate and facilitate imitation.

There are 3 types of Pranayama which we describe here:

- a) Pranayama (I) - Equalization of inhalation & exhalation

Technique: Stand firmly and comfortably. Breathe in and out equally, for 10 repetitions.

Benefits: Augments pleasant feelings throughout the body. It helps to calm the mind.

- b) Pranayama (II) – Technique: Place the hands on the sides of the chest. Make chest rise up and out as breath is taken in for 3 seconds and fall in and down as breath is released out for 3 seconds. Repeat 10 times.

Benefits: It activates the abdominal organs, provides a gentle massage, releases flatus and reduces fat in the abdominal region. These benefits are essential for children with autism. It helps in respiration and relaxation. In children with insomnia or sleep disturbances the calming effect helps them get good sleep.

- c) Pranayama (III) – Technique: Sit in the Asana for preparedness. Use little finger to close one nostril and breathe in from the open nostril. Now switch finger to close the other nostril and breathe out. Repeat 10 times.

Benefits: Has a sedative effect on the tone and rhythm of the heart and brain.

Asanas (Body positions/ postures & physical exercises) for autism :

In practice, asanas may be difficult to perform for children with autism. This may be due to their inattentiveness, hyperactivity, inability to sit at one place and follow sequences of complex commands. Simplify instructions for them and use demonstration. All the Asanas demonstrated here have an overall effect of mental and physical relaxation. Some children with autism have exceptional imitation abilities and the following Asanas may be beneficial. Ensure that yoga is practiced in a quiet and calming environment free of any distractions.

1. Parvatasana :

Technique: Sit comfortably with hands on the sides of the body. While inhaling (3 seconds) raise both the hands simultaneously, upward and above the head. Keep the elbows straight & join the palms. Pull the abdomen (stomach) slightly inside. Hold the breath and exhale (3 seconds) while bringing the arms down.

Benefits: Improves body balance, when child is so hyper its helps to control for steadiness of body.

2. Yastik asana :

Technique: Lie On back legs fully extended and arms extended and arms at the side. Be relaxed, inhale and raise arms above head, rest them on the floor and stretch. Holding breath, slowly stretch the body at full length, the toes and fingers pointing outward, as if trying to reach out (any attempt at maximum stretching of the body should be only during retention of breath). Repeat 3 to 4 times with in-between pose.

Benefits: Corrects faulty posture so that they can breathe properly.

Removes depression, and increases confidence.

3. Stretching :

Stretching is necessary for children with autism. Slow stretching is beneficial. Children need to do the stretching regularly as it prepares the body for asanas.

4. Eka Padasana :

Technique: Stand straight with the feet together and relax the body. Raise the arms above the head and interlock the fingers. Slowly bend forward from the hips, raise the right leg straight back. Keep the trunk, head, leg and arms in a straight line. In the final position the right leg, trunk, head and arms are all in one straight line. The left leg is straight and vertical. Focus the gaze on the hands. Hold this final position for some time and then slowly return to the starting position. Repeat the practice with the other leg, raising the left leg back.

Breathing : Inhale while raising the arms. Exhale while bending to assume the final position. Breathe normally in the final position. Inhale while returning to the upright position. Exhale while lowering the arms.

Benefits: This asana strengthens the arms, wrists, hips and leg muscles. It relaxes the lower back and helps develop nervous coordination.

Most effective asana for autism children, as it helps to increase concentration so child can cool down and focus on work.

5. Simhasana :

The Roaring Lion Posture in Yoga is suitable for people of all ages and types

(including old and weak) because it is relatively easy to perform. The posture is sometimes referred to as Bhairavasana.

Technique: Kneel down on the ground and place your body weight on your knees, calves and heels with the toes pointing back. Keep your head and spine erect with the knees about 6-12 inches apart. Press your palms on the respective knees with the fingers extended straight. This is the Thunderbolt Posture (Vajrasana). Open your mouth fully. Exhale through your nose and mouth, and simultaneously extend your tongue comfortably out of your mouth curving it toward the chin. Hold your breath with the abdomen pulled in. Widen your eyes, bare your teeth and stretch your facial muscles so that your face looks terrifying. Remain in this final posture for about 10 seconds or your breakpoint

Benefits: The Roaring Lion Posture (Simhasana or Bhairavasana) provides exercise to the facial muscles. It therefore maintains the firmness and lustre of the facial skin.

The posture is also good for the eyes in reducing strain.

The yoga posture helps in voice-related difficulties (e.g., stammering) and throat related problems (e.g., hoarseness and tonsillitis) because of the stretching of the tongue.

The yoga posture aids in better functioning of the carotid sinus, the sinus nerves, the larynx, the respiratory system as well as the thyroid and parathyroid glands.

The carotid bodies assist in maintaining normal blood pressure and heartbeats, whereas the breathing exercise helps the chest and abdomen.

6. Makarasana :

Technique: You need to lie flat on your abdomen Extend your legs and make sure that your heels point to each other. To clutch your right shoulder, bring your left hand under it Hold your left shoulder with the right hand as well. Let your elbows remain together, one upon the other on the practicing platform. Make sure that your face is placed in between your crossed hands. Unwind yourself and continue breathing normally for two to three minutes. Get back to the sitting position slowly

Benefits: It reduces hypertension

It is beneficial for the treatment of mental disorders

What are the specific benefits of yoga therapy in children with autism?

Yoga develops motor skills: Kids with autism frequently experience delayed motor development, which can be improved as yoga tones muscles, enhances balance and stability, and develops body, self in space and in relation to others.

Yoga improves confidence and social skills: Poor coordination often yields low self-esteem as kids may be singled out or teased for not moving or behaving like other



Figure 22.1: Sukhasana



Figure 22.2: Pranayama



Figure 22.3: Parvatasana



Figure 22.4: Vajrasana



Figure 22.g: Yastik Asana

children, or not excelling in sports and outdoor activities. By learning self control and self-calming techniques through yoga, they are likely to be more confident in interacting with other children and refine their social skills. Learning to work together in a yoga class can also increase confidence within group settings.

Yoga provides sensory integration: Children with autism often suffer from a highly sensitive nervous system and are easily over-stimulated by bright lights, new textures, loud noises, strong tastes and smells. Yoga's natural setting of dim lights, soft music, smooth mats, and "inside" voices creates a comforting environment largely protected from unknown or aggressive stimuli in which calming down becomes enjoyable. Yoga's physical poses allow nervous energy to be released from the body in a controlled manner, also leading to a calming sensation. Less stimulation means less uncontrollable behavior, outbursts and repetitive nervous movements.

Yoga engages the emotional brain: We all know that yoga is far from purely physical, and this combination of movement, music, breathing and storytelling activates the brain's emotional region. This encourages children to develop awareness of their emotions and those of others, as well as keeps their attention in the class.

Yoga is a mind-body practice in Complementary and Alternative Medicine (CAM) with origins in ancient Indian philosophy. The various styles of yoga used for health purposes typically combine physical postures, breathing techniques and meditation or relaxation. Practicing yoga yourself as a parent or teacher will help you deal with the stresses in your life. Caring for a child with autism is a challenge and the journey can be smoothed with the practice of yoga.

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23. Art Therapy

What is Art Therapy?

According to the American Art Therapy Association, "art therapy is a mental health profession that uses the creative process of art making to improve and enhance the physical, mental and emotional well-being of individuals of all ages. It is based on the belief that the creative process involved in artistic self-expression helps people resolve their conflicts and problems, develop interpersonal skills, manage behavior, reduce stress, increase self-esteem and self-awareness, and achieve insight."

Why is art therapy used in Autism?

One of the major characteristics of autism spectrum disorders is difficulty with verbal and social communication. It is seen that in some cases, people with autism are literally non-verbal i.e. they are absolutely unable to use speech for communication. In the other cases of autism, persons have a hard time processing language and turning it into smooth, easy conversations. Children with autism also have tough time understanding faces, expressions and body language.

Many individuals with autism have an extraordinary ability to think visually i.e. "in pictures." Many can put that ability to good use, e.g. in processing memories, recording images and visual information, and expressing ideas through drawings or other artistic media. Art is a form of expression that requires little or no verbal interaction which could open doors of communication for a child with autism.

What are the benefits of art therapy in autism?

Research pertaining to the impact of art therapy on individuals with autism is somewhat sketchy. However, listed below are a few positive results of art therapy:

- Improves the ability to imagine and think symbolically
- Increases the ability to recognize and respond to facial expressions
- Increases the ability to manage sensory issues (problems with stickiness, messy activities etc.)

- Improves fine motor skills
- Improves social skills

Easy Art Therapy Strategies:

1. Finger Painting :

You will need a white chart paper and different water colours or paints (children friendly and non-toxic) for finger painting. You could let the child use his fingers as the sensation of cool paint on the fingers is an enjoyable stimulation and it allows a child with autism gain more control over painting as opposed to using a paint brush. For kids with autism who find the sensation of the finger paint unpleasant, rubber gloves could be used. Encourage the child to be creative and appreciate his/her work.

2. Clay :

For this activity you need dry clay placed on a plate. The child needs to work with his hands. Encourage the child to feel the clay as it provides a soft and enjoyable sensation. Children with autism can mold the clay into shapes and different things or objects. Again ensure the use on non-toxic, anti-microbial clay in different, attractive colors.

3. Shaker Jars :

For this activity you need shake jars and various small objects or things (depending on the child's likes). For example; you could create shake jars that hold colourful and reflective objects. Also you could fill the jars with liquid soaps, marbles, rocks, balls, glitter, sequins, etc. This activity could teach children how different objects could reflect in water and it could also make the child aware of different objects being used. Such objects can also help improve eye-contact.

4. Photography :

Provide a camera, so that your child with autism can take photographs and create images. This enables children with autism to share their worldview with others. You can pin photographs up on the wall or refrigerator. This could increase the awareness of the child about the things and people around him.

5. Collage :

Schedule a nature walk so children with autism can collect flowers, barks, rocks and leaves to create a nature collage. Then glue different objects to create the collage. A nature collage teaches kids with autism to interact with the surroundings and explore the outside world.

6. Everyday Objects Art :

Take away the paint, clay, glue, markers and paper and encourage kids with autism

to create art with everyday objects. Art can be created from objects such as cardboard, threads, grains, gum and tin foil. This encourages kids with autism to become aware of their surroundings, interact with the environment and discover the potential of creating art from everyday life.

7. Fabric and Textile Art :

This includes pillow making, quilt making, weaving, needle crafts and other fabric based art. Some instructions and demonstration may be required for participants to learn sewing and other craft techniques. Modifications and adaptations can be incorporated for those who need assistance.

Not all qualified art therapists, however, have specific experience in working with people on the autism spectrum. While extensive experience may not be critical, it is very important that the therapist you choose understands the specific issues, challenges and strengths associated with autism, and more particularly your child. Art therapy in groups can have additional benefits of improving interaction skills and communication. The usefulness of art therapy is not only limited to children but has been established for people of all ages, including adults.



Figure 23.1 : Group Art Therapy



Figure 23.2 : Finger Painting

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24. Play Therapy

What is Play Therapy?

"Play is the method by which a child communicates with, and process information from the world around him". Hence, play is an essential part of a child's world. It is the means by which a child learns and copes with his or her environment.

Normally, children prefer the company of other children rather than being alone. However, for children or adults with autism, the same natural activities become a difficult task. Children with autism use toys in a very inappropriate manner; for example biting, banging or spinning them. Their play behaviors are also very repetitive. They often lack the ability to pretend play (e.g. dressing up a doll, or pretending to be a teacher) or imitate others. They usually have difficulty initiating or engaging themselves in play activities. Even if they do so, it may be the repetitive use of a toy in an inappropriate manner. They may simply line up toys in front of them, in different patterns. Problems in verbal and nonverbal communication (limited use of eye contact, facial expressions, conventional gestures, or spoken, signed, or written words to ask for objects) both notably affect the capacity of children with autism to enter into, coordinate, and sustain social play with peers. Children with autism face challenges while playing with peers as they have severe and persistent problems in social communication, inattention, imitation and social responsiveness. They need to be taught about both, the "desire to play" and "the skills" needed to do so.

What toys are therapeutic for children with autism?

It is important to remember that the whole idea of 'toys' is fun and a source of enjoyment for the child. It should not evoke any stress, fear or anxiety in the child. Children learn through play and develop many core concepts like colors, body parts, animals, fruits, clothing, sequencing, imitation, etc. Parents, teachers, and caregivers can also consider play in developmental domains in their choices of toys and materials for children with autism. They will want to include a balance of toys for different types of play, as suggested in the following list:

Gross-Motor Play :

- Large blocks
- Transportation toys
- Climbing equipment
- Tricycles, wagons, Big Wheels, and so forth
- Woodworking equipment and materials (child-size hammers, workbench, vise, screwdrivers, scrap lumber, etc.)

Fine-Motor Play :

- Clay
- Puzzles
- Art supplies (finger and water paints, brushes, markers, crayons, scissors, etc.)
- Beads for stringing
- Construction materials (small blocks, Legos, Lincoln Logs, etc.)

Language and Literacy :

- Books
- Writing materials (notepads, individual chalkboard, pens, pencils, old typewriters, sand trays, etc.)
- Thematic props (teddy bears for "Goldilocks," puppets, etc.)

Cognitive Play :

- Simple board games
- Simple card games
- Objects from nature (leaves, bird's nest, feathers, etc.)

Sociodramatic Play :

- Dolls and stuffed animals
- Props for dramatic play (hats, neckties, child stethoscope, eyeglasses with lenses, etc.)
- Miniature life figures
- Housekeeping equipment and props (child-size broom, dishware, table and chairs, etc.)

How do you teach your child 'to play'?

Play skills can be taught by breaking skills down into small sequential steps. Many activities may be disliked because they perceive themselves to be unsuccessful at them. Sometimes changing the equipments, the rules or the order in which the activities are performed can make a dramatic difference in the individual's enjoyment. You could

always modify the rules of the game for the child, depending on his needs or his capability.

Using structure (set patterns) could help children develop a social or leisure skill. Children with autism learn best in structured situations. One of the first considerations for learning how to play and occupy leisure time is to set aside a place especially for that purpose. Areas that are not too large and have some definable boundaries help suggest to the child what can and what cannot be done. Arranging materials or equipments for play in that space can reinforce the concept. Materials are an important consideration for eliciting the child's interest. Imitations and story forms can be used to help the child play.

A few play therapy strategies that parents can use for autistic children :

- Matching and sequencing games help in developing concepts, pattern matching, and categorizing and boosting short term memory.
- Manipulative play activities can be used to show children how to interact with objects and the environment around them. For example; putting together puzzles and stacking blocks could teach them perception and problem solving. When your child is unable to understand the concept of joining the puzzle pieces, you need to hold the child's hand or demonstrate to the child the technique to solve the puzzle step by step. After a couple of demonstrations, monitor the child's level of understanding and then encourage him or her solve the puzzle.
- Exploratory play activity such as dropping a ball into a hole introduces cause and effect, analyzing abilities and helps with sensory development of the child.
- Symbolic play activities encourage autistic children to pretend that an object is something else. For example, the child could be taught to imagine a bottle to be a microphone; this could help the children with autism develop laterality and thought flexibility.
- In functional play, you could provide appropriate sound effects and reactions for a toy or everyday object. Functional play is where a child imitates appropriate or learned responses. For example, the child may pretend to take a drink from a glass, and then wipe his or her mouth.
- Structure playtime so that there is continuity and repetition. Use familiar objects, but introduce new materials or different types of toys to keep activities spontaneous and fun.
- Use role-playing and social play to mimic real life situations. Usually children with autism learn social interaction in a better way, especially when they experience it or when it's taught to them step-by- step. An example of role-playing is to sit down with the child and teach him how he should respond when there are guests at home (smile or say "hello" or gesture "Namaste").
- Toys that focus on co- operative play can be an effective way to promote the

development of social skills like sharing, turn taking, communication and imitation. For e.g., board games are particularly good for the reinforcement of these skills.

- Sensory issues are quite common with autism and playing can be used as an opportunity to address their needs with play that integrates several kinds of sensory inputs. For example, musical toys that provide visual stimulations with lights or bright colors can be an excellent choice for children with autism. Sing along videos are great for auditory stimulation as well as helping with verbal skills.
- Puzzles are wonderful toys to improve fine motor coordination and if they are chosen with educational themes, such as letters, words, numbers, etc., concepts can also be learnt.
- Trampolines, bicycles, jump ropes etc. can be used to enhance muscle coordination, balance, and movement and can stimulate the motor-planning and languages centers in the brain. Children with increased hyperactivity could benefit from these physical play activities.
- Many children like to play with water. You could take half a bucket or a small tub of water and give the child things to throw into the water like toys, pebbles, etc. You could also place things in the water and request the child to pull them out of water.
- To teach shapes, you could draw a big circle on the floor and take turns to jump in and out. If the child has difficulty in jumping then you could ask him to "step" instead of "jump". You teach different shapes like square, triangle etc. to reinforce the concept thorough such a game.
- Introduce play in groups, challenges, targets or competitions only at a much later stage.
- Taking the help of some other supportive and helpful children, to involve your child into group play can be useful. Initially you may be required to stick around to aid your child and ensure safety.

Children with autism not only need appropriate toys to play with, but also need to be taught 'how to play'. If you have difficulty in finding a qualified play therapist then you need to get down on the floor and actively teach their autistic child the "right" way to play with a toy. This concept is well adopted in a treatment technique called "Floortime". As its name suggests, Floortime encourages parents to engage children literally at their level - by getting on the floor to play. Overall, Floortime aims to help children reach the developmental milestones crucial for emotional and intellectual growth. Consult your child's doctor and local autism support organizations for recommendations on finding a qualified play therapist. Play therapy can supplement almost any existing autism intervention plan. Depending on your child's needs, a certified floortime specialist or a child psychologist who has experience in using play therapy techniques for autism may be appropriate.



Figure 24.1: Group Therapy



Figure 24.2 : Child in Ball Pool



Figure 24.3 : Child solving puzzles



Figure 24.4 : Child with an educational toy



Figure 24.5: Child undergoing sand play therapy



Figure 24.6 : Child playing on peg board



Figure 24.7: Pretend play



Figure 24.8 : Child playing with the pyramid ring along with the therapist

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25. Music Therapy

What is Music Therapy?

Music is an ancient form of communication, common to all human cultures. It requires no verbal abilities, and it can be adapted to meet the needs and tastes of absolutely everyone. Music therapy is a well-established technique of using musical interaction to help individuals with a wide range of cognitive (thinking, understanding, attention and concentration abilities) and emotional challenges to improve their ability to function. By interacting with adults and children on the autism spectrum, musical therapists can help build skills, lower anxiety, and even develop new communication strategies. Music therapy has become an increasingly popular treatment option for autism.

It's important to note that music therapy is NOT the same as musical instruction. If your aim is to have your child build vocal or instrumental skills, you'll need to find an instructor instead of or in addition to a music therapist.

Why do children with autism have an affinity for music?

It has been suggested that people with autism have a particular affinity for music. Autism is unusual in that, a proportion of people with the condition (around one in ten) show abilities inconsistent with their overall cognitive skills (thinking, understanding, attention and concentration abilities) - sometimes, far in excess. One such skill is music.

Some individuals may have better musical skills than might be expected, while a few may be prodigiously talented or also known as musical savants. Musical savants typically have special abilities, such as being able to memorize and recite a new piece of music, having heard it just once. One hypothesis is that, without the



Figure 25.1 : Affinity for music

attention usually absorbed by social interactions, more of the brain's processing power can be devoted to other tasks, such as music. For mastery and performances, extensive practice and endless rehearsals are needed to excel. The characteristic repetitive behaviors of these children can be channelized into such purposeful activities (for example, playing musical instruments).

Role of a Music Therapist:

Assessment: The therapist may assess your child to determine the child's needs and abilities. Because music therapy is often used along with other therapies, the therapist might also consult the child's doctor or other therapists.

Goal-setting: An individualized music therapy program is developed based on the child's needs.

Activities: The sessions consist of activities designed to meet the child's individual needs. These could include song writing, moving to music, and singing, playing instruments, listening to music, working in groups and improvising.

During a music therapy session, children have the freedom to behave in ways that allow them to discover and express themselves when they want and choose. They can make noise, bang instruments, shout and express and experience the pleasure of emotional satisfaction. Sessions can be conducted on a one-on-one basis or in a group. Children typically attend once a week, for about 20 to 50 minutes. The duration of the therapy depends on the needs of the child.

Evaluation: The program is regularly evaluated to make sure it is working well.



Figure 25.2 : Initial lack of interest



Figure 25.3 : Increase in the level of interest and awareness

What are the benefits of Music therapy in Autism?

For people with autism spectrum disorder (ASD), music therapy uses interactive musical activities to improve social and communication skills. The aim of music therapy is to:

- Improve self-awareness
- Increase social awareness

- Explore the expression of emotions
- Increase motor/ perceptual (receiving, understanding environmental information and generating appropriate bodily responses) skills
- Increases independence
- Improving language comprehension (understanding)
- Encouraging the desire to communicate
- Making creative-self expression possible
- Reducing non-communicative (meaningless, irrelevant) speech
- Decreasing echolalia (uncontrolled and instant repetition of the words spoken by others)

The National Autistic Society (UK) claims that "music can stimulate and develop more meaningful and playful communication in people with autism. Research has shown positive effects, however there is a need for extensive research.

How does music therapy help families of individuals with diagnoses on the autism spectrum?

- An individual's growth through music therapy may improve the quality of life for the whole family. If the client's behavior is improved, there may be less stress or strain on other family members. In addition, with an increase in skills, the client may become more independent and aware and more able to interact and communicate with others.
- Music therapy can provide additional opportunities for positive interaction and building relationships among family members and the client. Greater family cohesiveness, support, and coping skills may be achieved through shared, equal music making during sessions or in the home environment.
- Music therapy interventions can teach family members alternative ways to interact, socialize, and communicate with their loved ones.
- Music therapy can help promote generalization/transfer of skills in sessions to the home environment.

Music therapy is conducted by professional therapists who are experienced in playing musical instruments and who have the experience of catering to the needs of children with autism. It is very important that therapy session should be conducted by a trained and an experienced musical therapist. A professional who specializes in autism can suggest different treatment for autistic's that can have a significant positive effect on their behavior.

"The ability to appreciate and respond to music is an inborn quality in human beings. This ability usually remains unimpaired by handicap, injury or illness, and it is not dependent on musical training."

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26. Dance Therapy

Dance is a form of art, involving direct expression through the body, which provides an intimate and powerful medium for therapy. The American Dance Therapy Association defines dance as "the psychotherapeutic use of movement as a process which furthers the emotional, cognitive and physical integration of the individual." Dance therapy involves the body and the mind. Dance as a therapy effects the changes in feelings, cognition, physical functioning and behavior.

How does dance therapy work in autism?

Dance therapy works on increasing the range of movement, cognition, decision making and self-esteem. It also deals with the ability to cope with change and stress. The experience of dance can help a child with autism open up to the possibility of connecting to others. Social interaction is very difficult for a child with autism to achieve and when a child with autism is encouraged to dance to rhythms and mirror the therapist's moves, it leads to the satisfaction of belonging to a group.

The combination of music and dance helps the brain to reorganize itself. During dance, the child processes music, learns new movements, performs movements to that music, and then repeats it a couple of times.

The processes of hearing, listening, processing, executing and repetition enable a child's brain to forge new pathways, engaging both the right and left side of the brain. A dance therapist works to increase the child's self-awareness through expressive movements. They try to draw the attention of the child to the feeling of the bodily senses that are created as a result of dance therapy. Dance therapy is believed to release muscular tension in the body i.e. emotional or physical



Figure 26.1 : Dance therapy

as it increases the flow of energy in the body. It is important that a therapist having the experience of working with children with autism conducts this innovative therapy for your child.

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27. Animal-Assisted Therapy

Animal-assisted therapy (AAT) is a type of therapy that involves an animal with specific characteristics, becoming a fundamental part of a person's treatment. The Delta Society's Standards of Practice for Animal Assisted Therapy (1966) defines animal assisted therapy (AAT) as an intervention with specified goals and objectives delivered by a health or human service professional with specialized expertise in using an animal as an integral part of treatment.

Animal-assisted therapy can vary from something as simple as bringing a pet into the home like a pet dog or a cat to something as structured as programs that offer horseback riding or swimming with dolphins. Interacting with animals can help children with autism to develop physically and improve their strength, coordination, and physical abilities. Most importantly the relationship formed with animals can help autistic children have a better sense of well-being, more self-confidence and can offer transferable skills of empathy and relating to others.

Animals Used in Animal Assisted Therapy :

1. Dogs

Dogs especially those who, have grown up with the family learn early to anticipate inappropriate behaviors right away. They help alert parents of potential danger, redirect the child toward safety, and provide emotional support for the child.



Figure 27.1 : Animal Therapy with dogs

2. Horses :

Hippotherapy or horse therapy, uses rhythm and balance on the horse to help increase balance, relax muscles and increase hand and eye coordination. Due to the excitement of riding, often the non-verbal child will speak to the horse to get it moving, aiding in the improvement of the child's speech and social skills.



Figure 27.2 : Animal Therapy with horses

3. Cats :

A cat can provide a watchful eye to a child with autism. Cats can alert their owners to danger by sitting on their chest or using their paws to get attention.

Other Animals which are used in Animal Assisted Therapy which are reported to have increased communication and motor abilities of children with autism are Dolphins and Tortoise.

What are the goals of Animal Assisted Therapy?

- Social and Emotional development
- Communication skills
- Behavior modification
- Self-expression
- Problem -solving
- Skill acquisition:
 - Communication skills
 - Gross and fine motor skills
 - Care taking
 - Assertiveness

What are the benefits of owning, an animal at home?

Owning a pet at home can help children with autism in the following ways:

Helps to overcome sensory defensiveness.

Helps the child to relax and maintain a better state of mind.

Helps the child learn about unconditional love.

Building and maintaining social skills

Increasing attention span.

Enhancing problem-solving skills.

Allowing a mirror for negative behaviors. Animals do not like loud screaming or tantrums, and will often shy away from them. If the child wants to spend time with the animal, he will begin to change his behavior.

George Eliot (1857) in his book Mr. Gilfil's Love Story, Scenes of Clerical Life once stated that "animals are such agreeable friends - they ask no questions, they pass no criticism." His comments seem to be very appropriate to our concluding remark for this chapter. The love and unconditional regard received from a pet or a therapy animal may represent a catalyst for emotional and psychological growth. A well - trained therapy animal working alongside a seasoned therapist may be a viable team used to promote various developmental and functional skills. On the other hand, families may want to consider adopting an animal for companionship. However, it is very important to keep in mind that the child does not suffer from any allergies that could be caused or aggravated due to contact with animals. Also, one must realize the importance of selecting a compatible pet and the need to be thought through to support not only the welfare of the person but also the animal.

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SUMMARY

Following a diagnosis of ASD early, prompt and appropriate management is essential. Management aims at reducing the primary issues including sensory problems, speech deficit, poor social interaction and behavioural issues. Hence, established interventions such as sensory integration therapy (occupational therapy), behavior therapy (psychological intervention) and speech therapy become mandatory for most children with autism during the early years. Supportive interventions are advisable to further the betterment of your child. These include the prescription of medicines and dietary regulations. Unconventional therapies namely yoga, art, play, music, dance and animal assisted are being explored by many today. Effects of these are also impressive. It is essential to choose interventions based on your child's need and requirements, as identified by professionals. Remember, that management is a long-drawn process and multi-disciplinary approach works best.



SECTION E

Recent Advances

28. Hyperbaric Oxygen Therapy for Autism

Hyperbaric oxygen therapy is a new form of medical treatment which is approved for 14 types of conditions and is now being studied extensively for autism. Few studies have been carried out to establish its safety and efficacy in autism. Preliminary reports have shown some beneficial effects like reducing hyperactivity, improvement in behavioral issues and speech. But these findings are not consistent in all studies. Even though, some children may benefit from HBOT, it is still not an established treatment.

What is Hyperbaric Oxygen Therapy?

Hyperbaric oxygen therapy (HBOT) is a safe, effective and a non invasive intervention used in a wide variety of medical conditions. "Hyper" means more and "Baric" means pressure, i.e. this therapy uses pressure to distribute more oxygen into body tissues such as brain along with blood, cerebrospinal fluid, etc. (1) The patient inhales 100% oxygen at a pressure three times greater than normal atmospheric pressure in an enclosed, specialized designed, pressurized chamber. (2) Under such a condition, lungs tend to breathe in more oxygen and also, more oxygen is dissolved in fluids such as blood plasma and CSF consecutively delivering more oxygen to the oxygen deficient body tissues. The body's healing process improves with more oxygen supply. Various studies have demonstrated use of HBOT in improving neurological functions, cognition, memory, etc.

How is the treatment administered?

HBOT is administered in two ways, either using a monoplace chamber or a multiplace chamber. The monoplace chamber holds a single patient whereas a multiplace chamber is a large chamber accommodating 5-6 patients. The patients are placed in these sealed chambers and the pressurized oxygen is administered either through a mask or directly into the chamber. (3) A session could last for 45- 60 minutes during which the patient can sit or lie down comfortably and watch TV, read a book, play on a video game or even take a nap. An adult can also accompany the child if the chamber is large or there

will be some provision for communication between the child and the adult from outside the chamber. Children are allowed to drink water to adjust to the ear pressures.



HBOT: MECHANISM OF ACTION

- Increase oxygen concentration in hypoxic or ischemic tissue
- Angiogenesis (growth of new blood vessels)
- Decrease cell death (apoptosis)
- Increase healing
- Increase circulation of endogenous stem cells
- Increase anti-inflammatory hormones
- Down regulate inflammation
- Increase bacterial killing by WBCs
- Inhibit bacterial toxin production

How does HBOT work in autism?

As discussed in the earlier chapters, the underlying pathophysiology of autism includes cerebral hypoperfusion (decreased blood flow), neuroinflammation (inflammation of tissues of nervous system), immune dysregulation (weak immune response), oxidative stress (excess of free radicals), etc. HBOT overcomes cerebral hypoperfusion by providing more oxygen to the brain, and causing angiogenesis (forming new blood vessels). Hypoperfusion often results in hypoxia which further leads to apoptosis (cell death). HBOT improves hypoxia and hence prevents apoptosis. (4) HBOT helps reduce the neuroinflammation by producing anti-inflammatory molecules. The increased

pressure also regulates the immune system of children with autism. By targeting these issues, HBOT helps in improving the affected functions such as cognition, memory, behaviour, speech, etc of these children. HBOT also functions as an antibiotic as it helps to decrease the abnormal pathogens in the gut often found in children with autism and improving the dysbiosis. (5) Recent studies have shown that HBOT mobilize stem cells/progenitor cells from the bone marrow. (6) These cells may help in forming new neurons, astrocytes and microglia thus, reversing the neurodegeneration (progressive loss of neurons) in conditions such as autism. The benefits of stem cells in autism will be discussed in detail in the next chapter.

Are there any side effects of HBOT?

When used according to the standard protocol, it is a safe therapy. But nevertheless, some side effects may occur. Barotraumatic injury (in the ear, nasal sinuses, lungs and teeth), oxygen toxicity, myopia, cataract, claustrophobia, anxiety are a few side effects. Inhalation of high concentration of oxygen under pressure may also result in seizures. Prolonged treatment of HBOT may also lead to chest tightness and toxic pulmonary effects.

Conclusion :

HBOT seems a promising treatment but it needs long duration of treatment (40 sessions) and also the results are not yet established. It is still not a definitive treatment or a cure. It can be used as an adjunct with standard therapeutic modalities taking into consideration the safety issues. It is recommended that before deciding on the treatment you discuss the details of HBOT with the specialist doctor and know whether it will help your child.

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29. Stem Cell Therapy in Autism

There is a new revolution in the medical world. A revolution that has taken the scientific world by storm. A revolution that was awarded the 2012 Nobel Prize in Medicine. A revolution that is redefining the words- incurable and untreatable. A revolution that is reshaping the way we now think about neurological disorders. A revolution that will forever change the world of our children with autism. This revolution is called "Stem Cell Therapy". It is not often that quantum leaps occur in our understanding and treatments of various medical conditions. But stem cell therapy is definitely one of those leaps. Rapidly developing advances in this field are forcing medical practitioners and scientists to completely rethink everything that was believed about various so called "incurable" conditions specially those involving brain and spine. However, whilst there is lot of hope about stem cell therapy, there is also lot of hype and it is important to make a distinction between these two. Also, there are lot of misconceptions about what stem cells are, the ethics of its use, the safety of the treatment and the effectiveness in various conditions/disorders.

In this section, we shall attempt to clarify all aspects of stem cell therapy. We shall initially discuss the basic facts about stem cells and how stem cell therapy is done. We will also present our own experiences and clinical results in a simplified way, along with case reports. We have also addressed the questions frequently asked by parents with regards to stem cell therapy. Almost all of the available scientific references have been listed at the end of the chapter, so that parents can source the original writing and get a complete perspective. This section concludes with a discussion on the dilemmas and debates around stem cell therapy. The purpose of this section is to put forth all the facts about stem cell therapy, thereby help parents to make an informed choice about whether they would want to opt for this treatment for their children.

29.1 Basics of Stem Cells and Stem Cell Therapy

Stem cells are defined as undifferentiated specialized cells, which can multiply manifold, can convert to any type of tissue of the body and have the ability to migrate to and repair the damaged tissues of the body. These cells exhibit a unique property of "plasticity" where in cells isolated from one tissue convert to cells of different tissues by crossing lineage barriers and adopting the expression profile of cells that are unique to other organs.

Types of Stem Cells

Stem cells are categorized based on their potential to differentiate into other types of cells.

1. Totipotent cells: These cells have the ability to differentiate into all possible cell types of the human body.
2. Pluripotent cells: A human embryo consists of three layers of specialized cells from which all different organs are formed. The pluripotent cells have the ability to differentiate into any of the three germ layers viz. endoderm, mesoderm and ectoderm.
3. Multipotent cells: These cells have the ability to differentiate into many types of specialized cells.
4. Oligopotent cells: These cells have the ability to differentiate into a few cells.
5. Unipotent cells: These cells have the ability to produce cells only of their own type, but are capable of self-renewal to be classified as a stem cell.

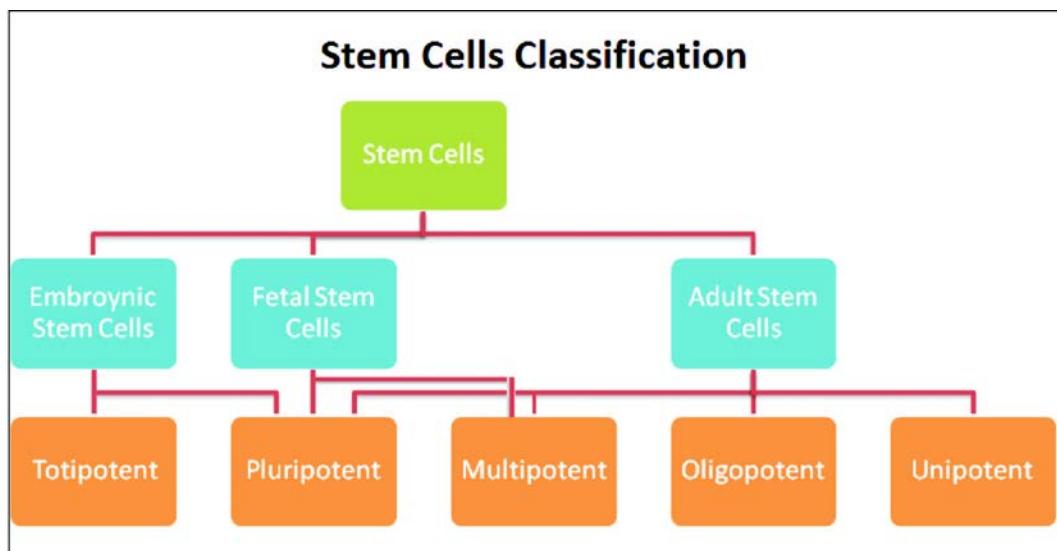


Figure 1: Classification of Stem cells

Stem cells are broadly classified based on their origin, as follows:

1. **Embryonic stem cells (ESCs):** These cells are pluripotent cells derived from a 4-7 day old blastocyst stage embryo. The cells are harvested from the inner cell mass (ICM) of the blastocyst. (See figure) They can be indefinitely maintained and expanded as pure populations of undifferentiated cells, in culture. Inspite of their clinical potential in tissue repair, these cells have triggered various ethical and moral issues as they involve destruction of human embryos. They also have tumorigenic side effects. They form tumor like teratomas. The likelihood of development of tumors in children cannot be overlooked as they have many years of life ahead of them for the tumor formation to occur.
2. **Fetal Stem Cells:** These cells are isolated either from the aborted fetus or from the extra embryonic structures of the fetal origin such as the amniotic fluid (fluid surrounding baby in the womb) and placenta. Fetal blood is a rich source of haematopoietic stem cells (HSC). Non-haemopoietic mesenchymal stem cells (MSC) are also found in the First trimester fetal blood. These cells have better homing capacity, greater multipotentiality and differentiation potential and lower immunogenicity as compared to the adult stem cells. Although these cells have a greater therapeutic potential they are also susceptible to infections. As the safety is not yet substantiated, fetal cells are not usually used for transplantation.
3. **Umbilical cord:** Umbilical cord stem cells are derived from the umbilical cord which connects the baby and mother at birth. These stem cells do not have any major ethical issues regarding their usage; however, availability can be an issue in different places. Umbilical cord contains a heterogeneous mixture of stem / progenitor cells at different lineage commitment stages. Cells are isolated from the cord blood. They consist of embryonic stem cell-like and other pluripotential stem cells, which can give rise to hematopoietic, epithelial, endothelial, and neural tissues. Various banks have evolved to collect and preserve the umbilical cord blood. But the utility of these centers is still questionable. The protocols and guidelines for collection and retrieval of cells are still being standardized.
4. **Induced pluripotent stem cells (iPSC):** To circumvent the ethical issues involved in the use of embryonic stem cells, pluripotent cells were generated directly from the patients' own cells. Induced pluripotent stem cells are non-pluripotent adult cells (somatic cells) which have been genetically reprogrammed to form pluripotent cells. But, to initiate the clinical trials involving iPSCs, the reprogramming efficiency and safety considerations are yet to be established.
5. **Adult stem cells:** These cells are multipotent stem cells, isolated from adult tissues. They include hematopoietic stem cells, bone marrow derived stem cells, adipose tissue-derived stem cells, neural stem cells amongst others. Adult stem cells are found in almost all the tissues of the body and help to maintain and repair organs and tissues throughout a person's life. Adult stem cells can be derived from the same patient, from either the hip bone or the fat/adipose tissue. These are the safest and most popularly used stem cells at present.

Major sources of adult stem cells

Bone marrow:

Anterior or posterior superior iliac crest (hip bone) is the preferred site for the bone marrow aspiration.

Bone marrow is a proficient source of autologous cells with distinct regenerative properties, which can be quickly harvested and are thus applicable for both chronic and acute diseases. The mononuclear cell fraction derived from the bone marrow is a heterogeneous population containing differentially matured B-cells, T-cells and monocytes, as well as rare stem cells such as hematopoietic stem cells (HSC), mesenchymal stromal cells (MSC), and endothelial progenitor cells (EPC). It has been observed that use of cell mixture is more efficacious than individual subfractionated cells of the bone marrow. They promote angiogenesis, mediate vascular repair, and express several cytoprotective growth factors and cytokines. These cells are also safe and due to its easy availability they are most preferred for cellular therapy. These cells are used for the treatment of various neurological disorders such as autism, cerebral palsy, stroke, parkinson's, spinal cord injury, etc along with diabetes, orthopedic conditions, cancers and wound healing.

Adipose tissue:

Adipose tissue derived stem cells (ASCs) are multipotent cells, found abundantly in fat tissue. They can differentiate into several lineages, including fat cells, cartilage cells, bone cells, neuronal cells, blood vessel cells, and heart cells. These cells are obtained either through liposuction. Mesenchymal stem cells make up the majority of the adipose derived stem cells. Due to their plasticity, they are a preferred alternative to the BMSCs. One of the major disadvantages of adipose derived stem cell is that they are not a completely homogeneous cell population and it requires a complicated isolating process.

Dental pulp:

A population of stem cells has been isolated from the human dental pulp known as dental pulp stem cells (DPSCs). They have an ability to regenerate a dentin-pulp-like tissue. DPSCs are a heterogeneous population of cells as they are composed of mesenchymal and other cells. These cells are readily obtained (from routine dental procedures such as removal of impacted third molars) and have been shown to possess properties similar to neural stem cells and mesenchymal stem cells. Under appropriate conditions, these cells also undergo neuronal differentiation. One of the disadvantages of DPSCs is that it takes longer to culture mesenchymal stem cells from teeth active tissue. Also, it is difficult to harvest a large quantity of stem cells from teeth.

No.	Types	Description	Description	Disadvantages
1	Embryonic stem cells	These are pluripotent cells obtained from the inner cell mass of blastocysts from the IVF clinics	These are pluripotent stem cells and have the ability to form any tissue of the body	Obtaining and processing these cells is tedious. There are various ethical, moral and religious issues involved in the use of these cells. They are also known to cause tumors.
2	Fetal Stem cells	The primitive stem cells located in the organs of the fetuses are referred to as fetal stem cells. They are pluripotent in nature.	These stem cells have a better homing and engraftment capacity as compared to adult cells	Obtaining and processing these cells is tedious. Not many studies have been carried out for the use of these cells
3	Bone marrow Stem cells	These are multipotent cells obtained from the bone marrow. They are a mixture of various hematopoietic and non hematopoietic cells.	Easily obtainable, high availability, high proliferative capacity, can have an autologous source, safe and no ethical issues involved	Incase of allogenic transplantation, there is a risk of immune rejection.
4	Umbilical cord blood cells	These cells are multipotent in nature obtained from the umbilical cord immediately after birth, which contains a rich source of hematopoietic stem and progenitor cells	Easy to obtain, high availability, do not produce strong graft-versus host disease, high proliferative capacity	Slow engraftment, storage issues, require quality control, after transplant, there remain no backup cells from same cord blood unit.
5	Mesenchymal Stem cells	They are multipotent cells that have the potential to differentiate into multiple lineages including bone, cartilage, muscle, tendon, ligament fat and a variety of other connective tissues	Safe, high proliferative capacity, No ethical concerns	Requires culturing of the cells before transplantation.

Sr. No.	Types	Description	Description	Disadvantages
6	Neuronal stem cells	These cells are isolated from various areas such as adult CNS including the spinal cord which have the potential to treat various incurable neurological disorders	No ethical concerns, specified to be neural lineage, cells from the affected individual can be obtained	Few cells available, difficult to expand, survive only for a few passages.
7	Adipose tissue stem cell	These stem cells are multipotent in nature and are obtained from the body fat.	Can be obtained in large numbers as they are available abundantly, easily obtainable	Their efficacy and feasibility in human use is yet to be proven
8	Muscle stem cells	Muscle stem cells are found in skeletal muscle tissue. They are activated in response to muscle injury.	Easy to obtain, contributes to muscle regeneration, pure isolation, easily expands in vitro	May have a risk of immune rejection in case of allogenic transplantation, their efficacy in humans is yet to be proven
9	Induced Pluripotent Cells	These are adult cells, genetically reprogrammed to form embryonic stem cell-like cells.	Same potential as embryonic stem cells without the ethical controversy, Can form any tissue in the body	If not fully mature can cause cancer, tend to age prematurely and have a high rate of cell death

How do stem cells work in autism

It is understood now, that the lack of oxygen supply to the brain and immune deregulation are the two key pathologies associated with autism. This in turn could be the cause of reduced functioning in this area. This coupled with an overall imbalance in the activity of the brain, is possibly responsible for the manifestations associated with autism.

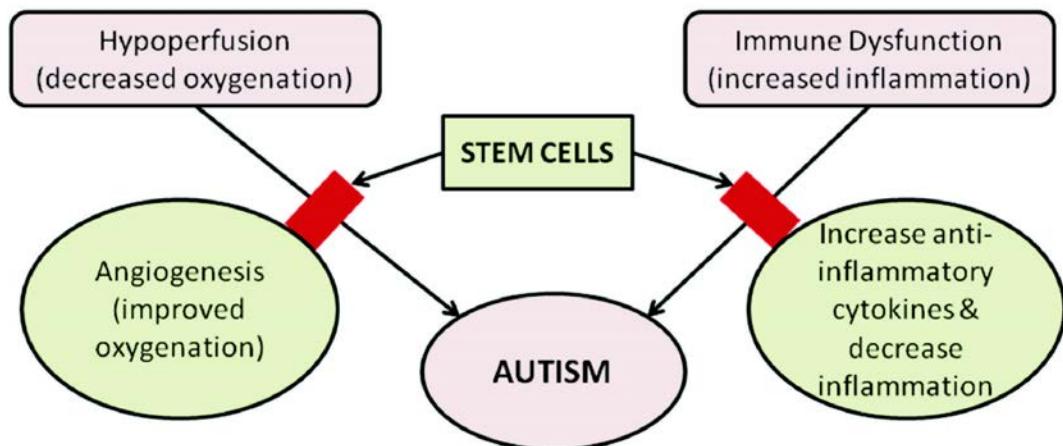
Researchers and doctors are now looking at regenerative therapy using stem cells as potential therapy for children showing symptoms of autism. The fact that stem cells possess the capability to multiply in many cells and form specialized cells different from the original cell ,can help in repair of the damaged brain tissue, forms the basis of this idea. Stem cells have the potential to repair the affected neural tissue at the molecular,

structural and functional level. They are known to address the core neuropathology of autism with the help of their unique paracrine regulatory functions that are capable of regulating cell differentiation, tissue and organ repair, and anti-inflammatory actions in the recipient.

Stem cells have been shown to possess the ability to modulate the immune response and enhance angiogenesis, thus bringing about therapeutic effects in autism. The treatment works by injecting mononuclear cells, into the central nervous system (CNS) of the patient. Stem cell transplantation increases the blood flow to the brain areas by virtue of angiogenesis, bringing in more oxygen and energy to the oxygen deprived cells, which in turn allows the cells to regain function.

Ichim et al and Siniscalco et al, in their review, have proposed the administration of stem cells as a novel treatment for both the pathologies of autism, i.e., abnormal immune function as well as cerebral hypoperfusion. The stem cells' immunomodulatory, paracrine, trophic and restorative effects, seen in other disorders, make them very logical and attractive tools for ASD also.

Stem Cell Therapy in Autism



Stem cells are actively involved in the formation of new tissues and thereby can also promote repair and regeneration. Their role, in the normal wear and tear of the body, appears to be assistance of repair and maintenance of normal tissue structure and function. Cell-based therapy could therefore potentially be used to treat a wide array of clinical conditions caused due to cellular damage. The process of deciphering the underlying mechanism of action of stem cells is a continuous process. However, years of experiments and studies have put forward few theories which either individually or in combination carries out the repair of the damaged tissues. Few of the mechanisms have been discussed below.

Plasticity, Pluripotency and Production

Stem cells have remarkable property of plasticity wherein they can cross the lineage boundaries. Transplanted bone marrow cells were reported to generate a wide spectrum of different cell types, including endothelial, myocardial, neuronal, and glial cells. Mesenchymal stromal cells (MSC) of the bone marrow can generate brain astrocytes. Enriched stem cells from adult mouse skeletal muscle were shown to produce blood cells. In most of these plasticity studies, genetically marked cells from one organ of an adult mouse apparently gave rise to cell type characteristics of other organs following transplantation, suggesting that even cell types once thought to be terminally differentiated are far more plastic in their developmental potential than previously thought.

The Paracrine Effect

Exploration of the various cellular mechanisms occurring in the process of stem cell renewal and differentiation, suggests that stem cell transplantation remodels and regenerates injured tissue, improves function, and protects tissue from further insult. These have also led to phase I and II clinical trials regarding stem cell treatment. Despite these encouraging advances, the mechanism of this protection is still not well-characterized. It was hypothesized that immature stem cells differentiate into the phenotype of injured tissue, repopulate the diseased organ with healthy cells, and subsequently improve function. Several lines of evidence suggest that stem cells may mediate their beneficial effects, at least in part, by paracrine mechanisms.

Paracrine signaling factors include cytokines and other growth factors, which are involved in orchestrating the stem cell-driven repair process through increasing angiogenesis, decreasing inflammation, preventing apoptosis, releasing chemotactic factors, assisting in extracellular matrix tissue remodeling and activation of resident/satellite cells which is discussed further in details.

Increased Angiogenesis

Stem cells produce local signaling molecules that may improve perfusion and enhance angiogenesis to chronically ischemic tissue. Although the particular growth factors contributing to this neovascular effect remain to be defined, the list includes vascular endothelial growth factor (VEGF), hepatocyte growth factor (HGF), and basic fibroblast growth factor (FGF2). VEGF is a strong promoter of angiogenesis. Chen et al. have recently shown that treatment with bone marrow stromal cells enhances angiogenesis by increasing endogenous levels of VEGF and VEGFR2.

Thus, VEGF, HGF, and FGF2 may be important paracrine signaling molecules in stem cell-mediated angiogenesis, protection, and survival.

Decreased Inflammation

Stem cells appear to attenuate infarct size and injury by modulating local inflammation.

When transplanted into injured tissue, the stem cell faces a hostile, nutrient-deficient, inflammatory environment and may release substances which limit local inflammation in order to enhance its survival. Modulation of local tissue levels of pro-inflammatory cytokines by anti-inflammatory paracrine factors released by stem cells (such as IL-10 and TGF-?) is important in conferring improved outcome after stem cell therapy.

Chemotactic Signaling

Evidence also exists that both endogenous and exogenous stem cells are able to "home" or migrate into the area of injury from the site of injection or infusion. MSC in the bone marrow can be mobilized, target the areas of infarction, and differentiate into target tissue type. Granulocyte colony-stimulating factor (G-CSF) has been studied widely and promotes the mobilization of bone marrow-derived stem cells in the setting of acute injury. This homing mechanism may also depend on expression of stromal cell-derived factor 1 (SDF-1), monocyte chemo-attractant protein-3 (MCP-3), stem cell factor (SCF), and / or IL-8.

Anti apoptotic effect

Stem cells have neuroprotective effect which causes the microenvironment of neural cells more conducive to growth and survival. This reduces apoptosis (programmed cell death).

Beneficial Remodeling of the Extracellular Matrix

Stem cell transplantation alters the extracellular matrix, resulting in more favorable remodeling, prevention of the scar, and prevention of deterioration in organ function. MSCs appear to achieve this improved function by increasing acutely the cellularity and decreasing production of extracellular matrix proteins such as collagen type I, collagen type III, and TIMP-1 which result in positive remodeling and function.

Activation of Neighboring Resident Stem Cells

Finally, exogenous stem cell transplantation may activate neighboring resident tissue stem cells. Recent work demonstrates the existence of endogenous stem cells. These resident stem cells may possess growth factor receptors that can be activated to induce their migration and proliferation and promote both the restoration of dead tissue and the improved function in damaged tissue

To sum up, although the definitive mechanisms for protection via stem cells remains unclear, stem cells mediate enhanced angiogenesis, suppression of inflammation, and improved function via paracrine actions on injured cells, neighboring resident stem cells, and the extracellular matrix. Improved understanding of these paracrine mechanisms may allow earlier and more effective clinical therapies

Remyelination

Myelin sheath is a covering around the nerve fibers. This sheath when damaged will lead to conduction delays of the signals. Loss of myelin sheath is called demyelination. Demyelination causes decreased brain function. Remyelination means repair of demyelinated axons with new myelin sheaths. Previous attempts aimed at regenerating myelin-forming cells have been successful but limited by the multifocal nature of the lesions and the inability to produce large numbers of myelin-producing cells in culture. Stem cell-based therapy can overcome these limitations to some extent and may prove useful.

Contrary to the general expectations that stem cells would primarily contribute to formation of tissue cells for repair, other mechanisms such as paracrine effects and remyelinations appear to be important ways via which stem cells seem to exert their effect. More basic research to understand these mechanisms is underway throughout the world.

Hence stem cells function in multiple ways to promote regeneration and repair, viz., via paracrine effects and improving function of neighbouring cells, reducing inflammation, improving angiogenesis, effecting remodeling of extracellular matrix, etc. Put together, they also induce plasticity in the brain and neuronal transformation.

Final effect in autism is seen via the improved metabolism in the brain as seen in PET CT Scan of the brain.

PET-CT SCAN OF THE BRAIN BEFORE STEM CELL THERAPY

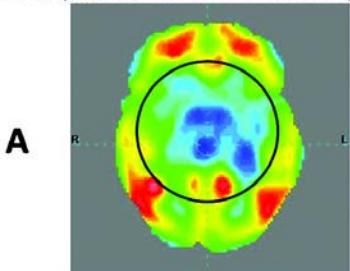


Figure A shows the PET-CT scan findings before stem cell therapy. The areas in blue show damaged part of the brain.

IMPROVEMENTS AFTER STEM CELL THERAPY

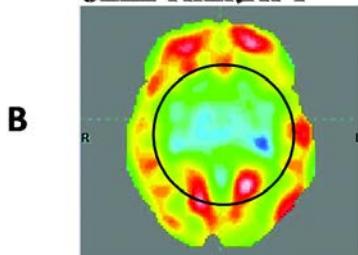


Figure B shows the improvement seen after stem cell therapy. Reduction in the blue area suggest repair of the damaged part.

How is stem cell therapy done?

The procedure for stem cell transplantation at Neurogen Brain and Spine Institute is minimally invasive, with simple steps. There is no major surgery or incision required. The procedure is carried out in only three steps.

- **Bone marrow aspiration:** Bone marrow is the place where blood is formed. In simple terms, it can be called a factory of blood. As is common knowledge, blood is formed in the hollow space of bones. The easiest place to take out the bone marrow is the hip bone.

This is done through a bone marrow aspiration needle, which is a thin needle inserted into the hip bone. Procedure is usually done under local anesthesia. For children and adults who cannot tolerate the procedure, sedation as required is administered. The entire time taken to do this is only 15mins to 30 minutes. Between 80ml to 120ml of bone marrow is aspirated, depending on the weight of the patient. The patient is then sent back to the room for about 3 to 3 and a half hours, till the cells are separated for the next step of the procedure.

- **Purification of stem cells:** On the same day, within 3-5 hrs, the stem cells are separated and purified in our stem cell laboratory by using a procedure referred to as density gradient centrifugation. Basically, stem cells have a fixed density and this property is used to separate them.

- **Stem cell injection:** Once stem cells are separated and purified (in about 3-3 ½ hrs), patient is taken back to the operation theatre. Injection of stems cells into the fluid around the brain and spine (intrathecal injection) is carried out using either an epidural needle (portex) or a spinal needle. Stem cells are first diluted in the CSF and then injected into the spinal space, through lumbar puncture. Lumbar puncture is a standard procedure where a needle is inserted into the lower back in between the two vertebral bodies (L4 - L5 level) to reach the fluid in the spinal canal.

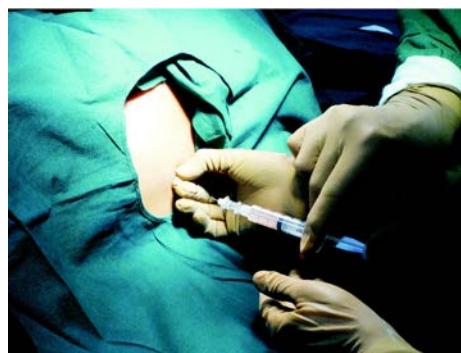


Aspiration of cells from the bone marrow



Separation and purification of stem cells

patient is taken back to the operation



Intrathecal administration of stem cells

Why bone marrow stem cells?

Bone marrow derived stem cells are one of the earliest stem cells to be used and have been researched widely. These cells are easily obtained from the same patient. Hence, they are safe, do not have any rejection issues.

When the blood compartment is not diseased, stem cells from bone marrow is a very easy and replenishable source of stem cells. It has been widely studied and researched. Hence, we know about its characteristics and what it can do very thoroughly. The bone marrow is composed of various different fractions of cells, each having its own function and role. These fractions are haematopoietic stem cells, mesenchymal or stromal stem cells, very small embryonic like stem cells, endothelial stem cells. Since, each of these have a different function, a cocktail of these cells, has a combinatorial action and hence more effective than infusion or transplantation of a single type of cell (eg. Mesenchymal stem cell alone). Also, these cells have not been associated with any tumor /cancer formation. Since, these are from the children themselves, no irreversible neurological deficit is seen.

Why stem cells are injected intrathecally (putting the cells into the spinal fluid)?

At NeuroGen, stem cells are transplanted into the spinal fluid, which flows all around the brain and spine, providing nourishment to them. Let us discuss about, what are the different ways that cells can be delivered to the brain.

The most direct way would be directly into the brain through guided method (stereotactically). This would be probably the most efficient way (if we can localize the problem to one area), but hugely dangerous and complicated. This would have a high risk of further brain damage.

The simplest and least risky route would be simply infusing the cells into the peripheral veins (just as we infuse intravenous fluids). However, the long route that the cells would have to travel needs to be kept in mind. The cells would need to go through the veins, then the various organs, liver, heart, the lungs, then through the arteries to the brain. Also, the blood brain barrier (the protective coverings around the brain) may again reduce the efficiency of these cells reaching to the region of interest.

The transplantation of the cells into the spinal fluid, hence, bypasses the barriers and provides a simple, minimally invasive and effective way of reaching the region of interest. In addition, increased levels of chemical factors, such as Neurotensin and Corticotropin releasing hormones in children with autism, further helps the stem cells to reach the brain tissue, by increasing vascular permeability and improving access to the brain.

Worldwide published scientific evidence & reviews on Stem Cell Therapy in Autism:

Published Clinical Studies

The first ever clinical study published in the world to give clinical evidence of the role

of stem cells in autism, had come out in August, 2013 from the NeuroGen Brain and Spine Institute, Mumbai. This is an open label proof of concept study of autologous bone marrow mononuclear cells (BMMNCs) intrathecal transplantation in 32 patients with autism followed by multidisciplinary therapies. All patients were followed up for 26 months (mean 12.7). The outcome measures used were Childhood Autism Rating Scale (CARS), Indian Scale for Assessment of Autism (ISAA), Clinical Global Impression (CGI), and Functional Independence Measure (FIM/Wee-FIM) scales. PET-CT scan recorded objective changes. It was found that out of 32 patients, a total of 29 (91%) patients improved on total ISAA scores and 20 patients (62%) showed decreased severity on CGI-I. On CGI-II 96% of patients showed global improvement. The efficacy was measured on CGI-III efficacy index. Few adverse events were reported, including seizures in three patients, but these were reversible and easily controlled with medications. The encouraging results of this leading clinical study provide future directions for application of cellular therapy in autism.

Table Change in the scores of CGI and ISAA scores pre and post intervention

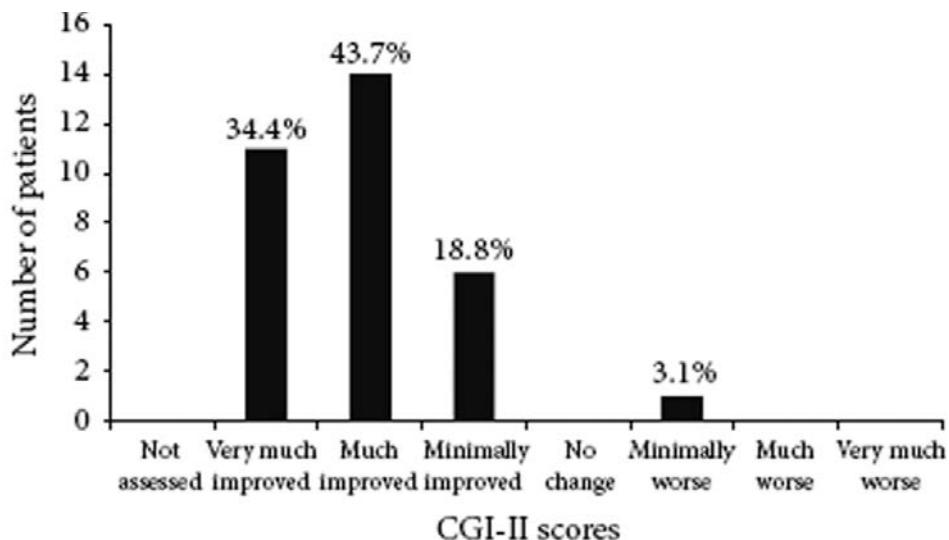
Scale	Median score before cellular therapy	Median score after the cellular therapy	Statistical significance
CGI - I	4.5	3	P < 0.001*
ISAA scale	115.5	97	P < 0.001*

*Statistically significant (level of significance at p<0.05)

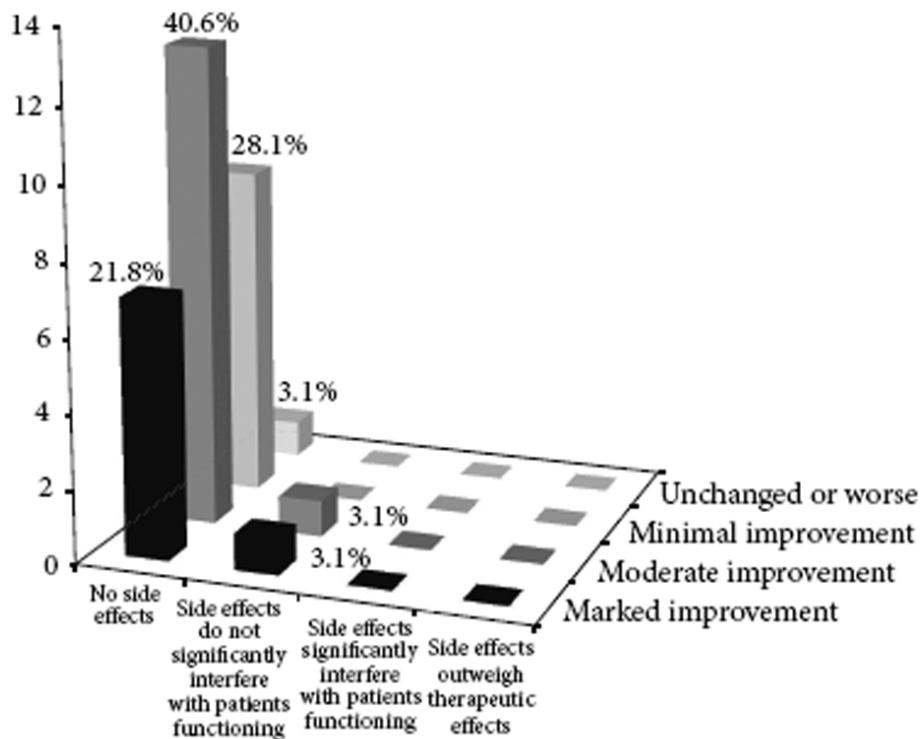
Table Change in the ISAA scores of individual domains measured pre and post intervention

ISAA scale domain	Median score before cellular transplantation	Median score after cellular transplantation	Statistical significance
Social relationship and reciprocity	35.5	13	P < 0.001*
Emotional responsiveness	23	20	P = 0.002*
Speech, Language and communication	13	11	P < 0.001*
Behavior patterns	29	10	P = 0.002*
Sensory aspects	21	17	P = 0.016*
Cognitive component	11	8	P < 0.001*

* Statistically significant (level of significance at p<0.05)



Frequency distribution of the participants on the CGI - III scale



The above figure demonstrates the percentage of people on varying degrees of efficacy of the intervention. This takes into consideration the side effects and the benefits observed.

The second study was published by Shenzhen Beike Bio-Technology Co., China, which studied the safety and efficacy of human umbilical cord mesenchymal stem cells (hUC-MSCs) and human cord blood mononuclear cells (hCB-MNCs) transplantation in patients with autism. This study comprised of 37 subjects diagnosed with autism, divided into three groups: CBMNC group, combination group (CBMNC and UCMSC), and control group (only rehabilitation therapy). Treatment safety was evaluated with laboratory examinations and clinical assessment of adverse effects. They used the Childhood Autism Rating Scale (CARS), Clinical Global Impression (CGI) scale and Aberrant Behavior Checklist (ABC) to assess the therapeutic efficacy at baseline (pre-treatment) and following treatment. They did not find any significant safety issues related to the treatment and observed no severe adverse effects. Statistically significant improvements were shown on CARS, ABC scores and CGI evaluation in the two treatment groups compared to the control at 24 weeks post treatment ($p < 0.05$). They concluded that transplantation of CBMNCs demonstrated efficacy compared to the control group; however, the combination of CBMNCs and UCMSCs showed larger therapeutic effects than the CBMNC transplantation alone. Other ongoing clinical trials worth mentioning, on similar lines, are being carried out, in Mexico, Greece and Ukraine.

Bradstreet et al in 2014 in a study involving children with Autism Spectrum Disorders, showed safety and efficacy of Fetal Stem Cells (FSCs) transplantation with an objective improvement in the scores on Autism Treatment Evaluation Checklist (ATEC) test and Aberrant Behavior Checklist (ABC) with regards to significant improvement in speech, sociability, sensory issues, and overall health.

Another study by Liu et al in 2013 suggested effectiveness and safety of human neural precursor cells (hNPCs) transplantation in children with autism. The results showed improvement on Autism Behavior Checklist scores compared to pre-therapy in the areas of social communication and language suggesting scope of stem cell transplantation as a possible treatment option for autism.

Published review articles

Ichim et al in 2007 presented a review suggesting combined use of Mesenchymal Stem Cells (MSCs) and cord blood CD34+cells as a promising treatment of autism. MSCs transplantation has shown beneficial effects in conditions involving immune dysregulation, whereas cord blood CD34+ cells are known to be potent angiogenic stimulators demonstrating positive effects in cerebral ischemia. Immune dysregulation and neural hypoperfusion being one of the causes of development of autistic disorder, MSCs and cord blood CD34+cells transplantation have shown beneficial effects in autistic children.

Siniscalco et al in 2012 suggested the use of MSCs transplantation as the best potential treatment option for autism owing to their immunomodulatory and angiogenic effects within the nervous system.

Dario Siniscalco, Italy, in his 2012 article discussed about the beneficial effects of immunomodulation brought about by stem cell transplantation in Autism Spectrum

Disorders, since immune and neural system dysregulations are the root cause of ASDs; thus suggesting that stem cell therapy could be a potent treatment for autistic syndromes, opening a new era in autism management.

DM Panchision in 2013 presented a report of meeting convened by the National Institute of Mental Health, Maryland which synthesizes the discussions based on progress and challenges in the use of patient-derived reprogrammed cells for mental illnesses such as autism spectrum disorders. The report suggested that the greatest progress has been made in reprogramming methods and agreed-upon standards for validating the resulting induced pluripotent stem cell lines.

Vaccarino et al, USA, in their 2011 annual research review on stem cell research in neuropsychiatric disorders like ASDs discussed about the advances in the understanding of neural stem cells and how nervous system develops from these cells which would help the scientists to study the disorders of the nervous system by rewinding and reviewing the development of neural cells. These advances in stem cells research have also allowed correction of some neuronal-specific abnormalities.

Siniscalco et al in 2014 in his review article discussed promising and impressive results of MSCs transplantation for the treatment of ASDs and the possible mechanisms of action of MSCs - stimulation of repair in the damaged tissue, synthesizing and releasing anti-inflammatory cytokines and growth factors; integrating into existing neural and synaptic network, and restoring plasticity.

Gesundheit et al, Israel, in 2015 highlighted the therapeutic properties of MSCs and hypothesized that the ability of MSCs to modulate a hyperactive immune system and to promote neurogenesis make MSCs an attractive potential therapeutic option for ASD.

Acab et al, USA, in 2015 suggested the use of iPSCs technology to understand the pathophysiology of ASDs and also open new avenues for treatment of ASDs.

Ebrahimi-Fakhari, Germany, in his 2015 review suggests that recent advances in the development of patient-derived induced pluripotent stem cell (iPSC) lines enable the identification of synaptic deficits in ASDs. Examples include Fragile X syndrome, Tuberous Sclerosis Complex and Phelan-McDermid syndrome.

Crook et al in their 2015 review discussed about the ability of induced pluripotent stem cells in representing a new tool to which will enable live human neural cell modeling of complex neurodevelopmental conditions such as autism.

Siniscalco et al in 2012 in their review discussed about the use of embryonic, induced pluripotential, fetal, and adult stem cells as a potential therapeutic option for ASDs. The review suggested the paracrine, secretome, and immunomodulatory effects of stem cells to be the likely mechanisms of application of stem cells for the treatment of ASDs.

Conclusion

Stem cell therapy using adult stem cells combined with a holistic neurorehabilitation program has now emerged as a simple, safe and effective treatment option for autism

that improves many of the symptoms otherwise difficult to treat and improves the overall quality of life. The functional improvements seen after stem cell therapy give the children with autism a greater degree of independence thus helping them integrate into mainstream society.

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(At NeuroGen Brain and Spine Institute, we have treated more than 250 patients of Autism till date with 91% of success rates. The clinical outcomes with their safety and efficacy have been published in 6 scientific papers in international peer reviewed journals. The full text articles are available on www.stemcellspublications.com).

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29.2 Clinical results of Stem Cell Therapy for children/individuals with Autism at NeuroGen Brain and Spine Institute

A total of 200 children with ASD were treated with autologous bone marrow stem cell therapy. Ninety one (91%) of all the patients, who underwent stem cell therapy showed functional and clinical improvements. The symptomatic improvements were as follows: Hyperactivity reduced significantly, there was increase in eye contact and attention span, there was a decrease in abnormal behavior, violence reduced dramatically, communication improved significantly and their social interaction became much better.

There were also objective improvements on various assessment scales such as Childhood Autism Rating Scale (CARS), Clinical Global Impression scale (CGI), and Indian Scale for Assessment of Autism (ISAA). In addition, in many of the patients, it was noted on the follow up PET CT scans of the brain done after six months of the stem cell therapy, that the areas of the brain which were non functioning prior to the treatment had improved in their functioning.

A detailed analysis of the improvements seen after stem cell therapy:

Presented are the details of the improvements seen in 150 children with autism who underwent stem cell therapy. Out of these 91% showed clinical improvements.

Improvements in Autistic Children after Stem Cell Therapy can be broadly classified as:

- A) Clinical/Neurological improvements: There was reduction in abnormal stereotypical behavior, reduction in self stimulatory behavior, improvement in eye contact, attention span, speech, communication skills and social interactions (shown in graphs/figures).

1. Hyperactivity:

Hyperactivity is one symptom, which improves most visibly. In 78% children, it was found that hyperactivity reduced significantly. Child would now sit at one place for a longer time and respond to commands better. This resulted in overall enhanced school performance as well as understanding and cognition. It is also worth mentioning here that in those children who were on medications for hyperactivity, it was possible to reduce the dose of the medicines.

2. Eye contact :

Reduction in hyperactivity was accompanied by improved eye contact in 91% children. This improved the child's command following and social interaction.

3. Attention span:

Improved attention span was noticed in 86% children. This improved the learning of the child, since the child would give attention and training was better in school.

4. Stereotypical behavior:

Almost 61% of the children showed reduction in abnormal stereotypical behavior. Parents found that hand flapping, hand waving, teeth grinding, rocking movements, nail biting, etc had reduced.

5. Self stimulatory behavior:

53% showed reduction in self stimulatory behavior, equal number showed reduction or stopping of self injurious behavior in the form of stimming.

6. Aggressiveness:

Violent behavior and aggression also reduced in 58% children. Children threw less temper tantrums, were less abusive and did less physical harm to parents and siblings.

7. Communication:

After stem cell therapy, it was observed that communication improved in many of the children. This was both verbal as well as non verbal. One child with autism, who was almost non verbal and was extremely hyperactive, once he calmed down after stem cell therapy, started gesturing his needs. He also started verbalizing in bisyllables and small sentences. His overall communication about his needs as well as his emotions to his parents and sister improved remarkably. Overall, improvement in communication was noticed in 63% of the children,

8. Speech:

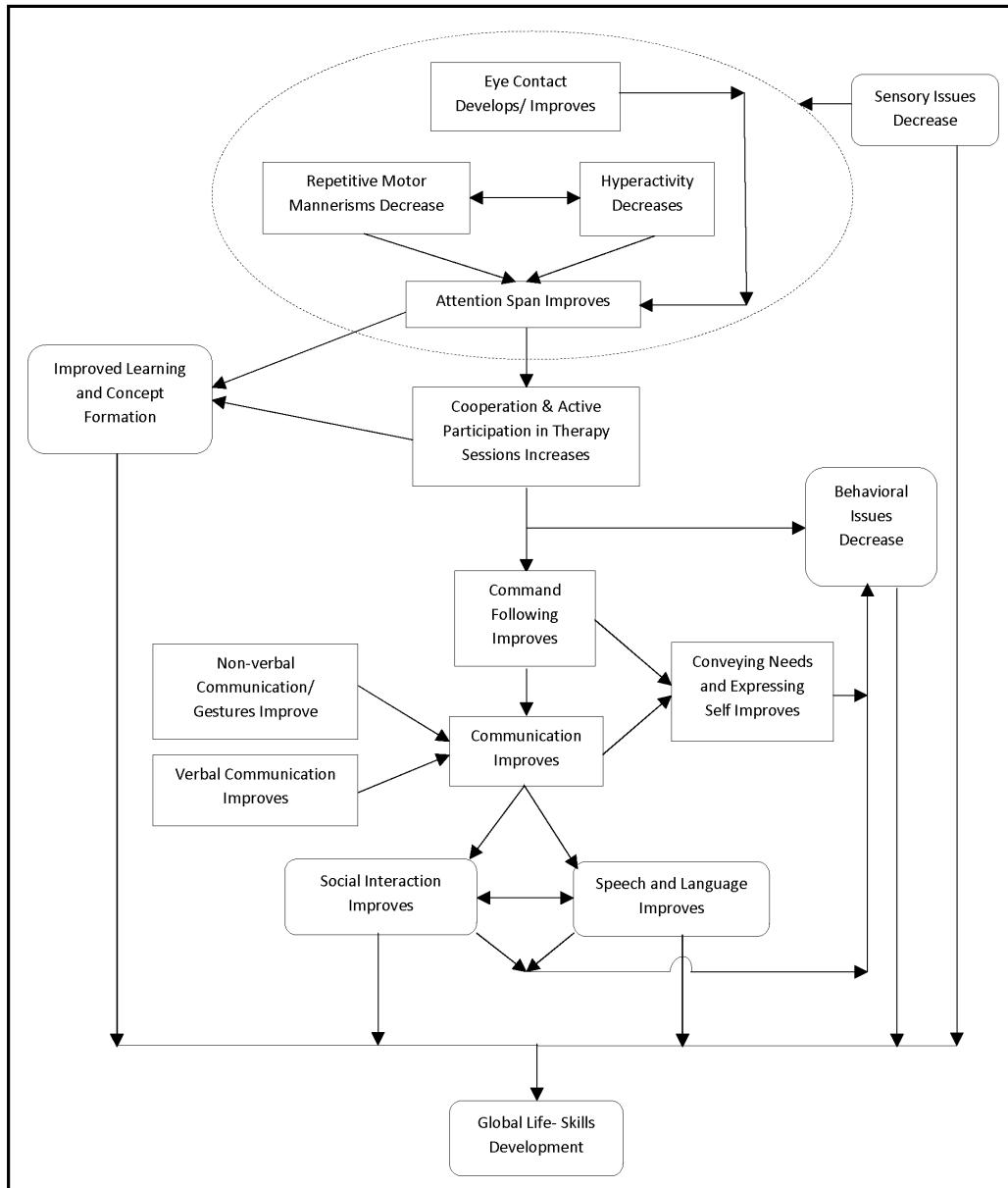
Improvement in speech was noticed in 64% of children. The children who were non verbal before could now verbalize in bisyllables and simple sentences. Also, clarity and relevance of speech improved.

9. Social interaction:

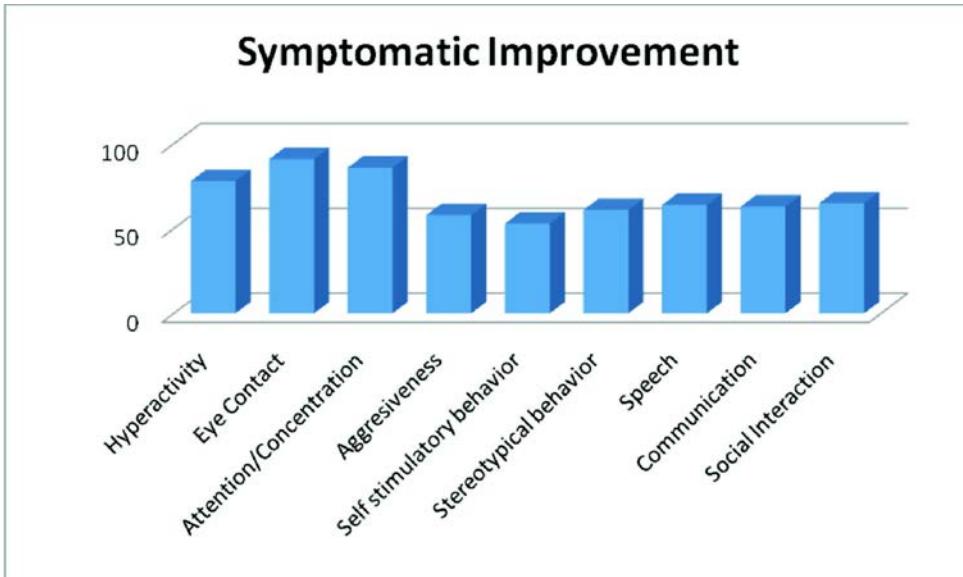
Along with a reduction in hyperactivity, attention to surroundings and awareness about surroundings also increased. This led to improved social interaction, along with an increase in initiative for different activities, which hitherto, was not observed in these children. Overall, 65% of the children improved in their social interaction skills.

10. Other symptoms:

Improvements were also noticed in other symptoms such as inappropriate emotional responses, sensory issues with touch, smell, and taste, freezing, insensitivity to pain, etc.

Fig. Schematic representation of clinical improvements after cellular therapy

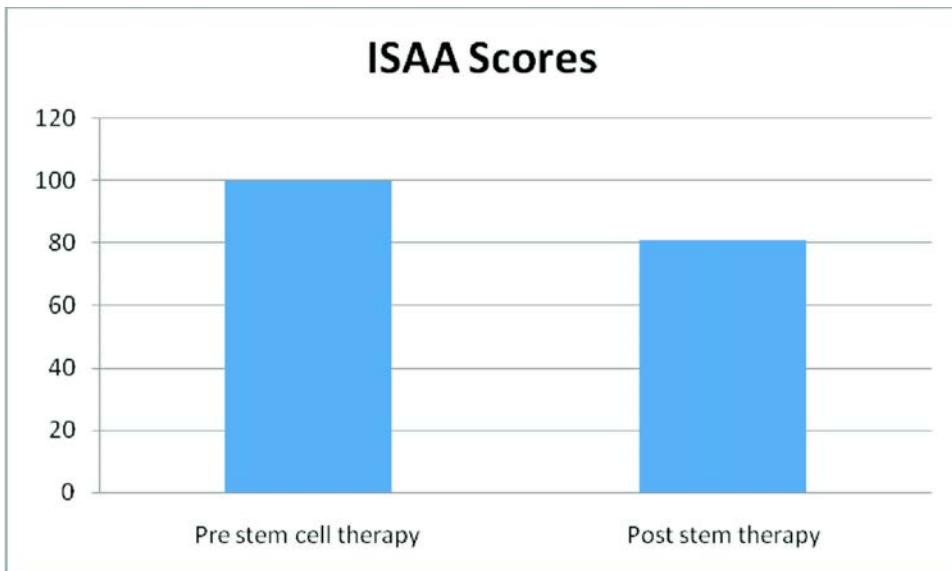
This figure shows proposed theoretical outline of observed changes after cellular therapy.



B) Improvements in the objective assessment scales:

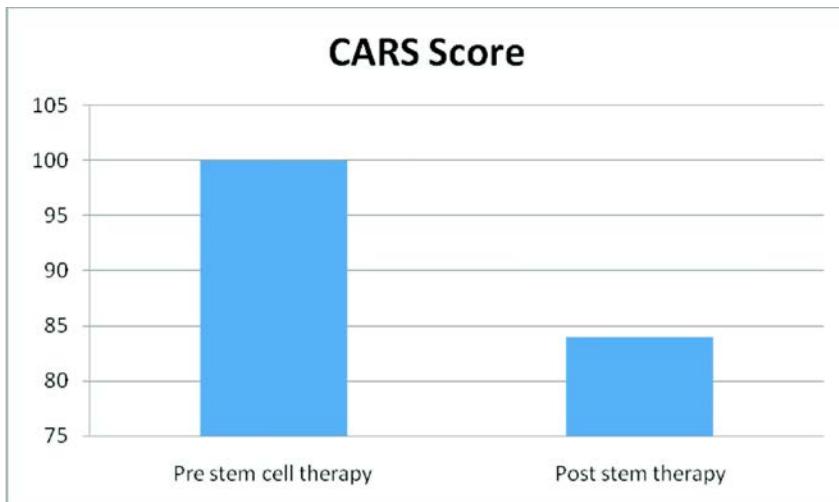
1. Changes on Indian Scale for Assessment of Autism (ISAA):

All the children were assessed on the ISAA (Indian Scale for Assessment of Autism) scale which quantifies the severity of autistic symptoms and enables the measurement of associated disability. The scores were noted before and six months after stem cell therapy. There was a significant improvement in the scores after the stem cell therapy. 81% of children showed improvement on the ISAA scale.



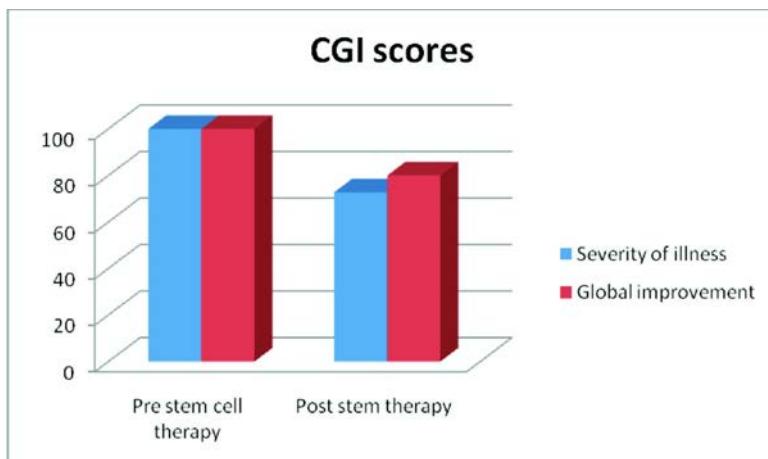
2. Changes on Childhood Autism Rating Scale (CARS):

CARS is a behavioral rating scale used to identify children with autism and to categorize these behaviors from mild to moderate to severe. The lower the score on CARS, the fewer autistic behaviors the child exhibits; the higher the score, the more autistic behaviors the child exhibits. The scores were noted before and after six months of stem cell therapy. There was a reduction in CARS score of 84% children showing reduction in the presence and severity of abnormal behavior.



3. Changes on Clinical Global Impression (CGI) scale:

Another scale used for monitoring the children is the Clinical Global Impression (CGI) scale. This is used as a clinical research tool to measure the severity of the illness along with the efficacy and response of the intervention/treatment in patients with autism. This scale also revealed improvement, when performed before and after the stem cell therapy, in terms of, the severity of illness (improvement in 73%) and global improvement (in 80% children; either improved or same).



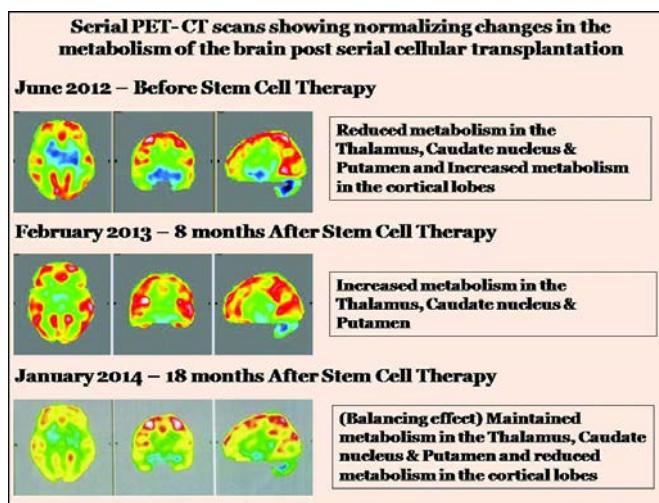
Monitoring of adverse events

A close monitoring was done for all 150 patients post stem cell therapy for occurrence of any minor or major side effects. No major side effect of the therapy was noted in any patient. A few patients had spinal headache, nausea and vomiting which resolved with medicines and fluids within a couple of days. Initially few patients who had history of seizures or abnormal EEG, developed seizures post cell therapy. To avoid this prophylaxis with anti-epileptic medicines was started. Since then, none of the children had seizure as a side effect after stem cell therapy. It is noteworthy that even children with seizures showed significant clinical improvements.

C) Objective improvements on SPECT/PET CT Scan Brain:

- Most of the children with autism have grossly normal brain morphology on MRI scans of the brain. However SPECT/PET CT scan of the brain, which shows abnormalities in brain perfusion/metabolism, is now emerging as a useful imaging technique to identify the affected areas as well as to quantify the severity of the damage.
- These imaging were done before the stem cell therapy and six months after the therapy. Changes were seen in the FDG uptake and metabolism of brain areas in the repeat scans as compared to the previous scans.

Below are examples of PET CT brain of children with autism performed before and six months after stem cell therapy.



The above figure shows the changes in the brain of a child with Autism after serial stem cell therapies. The PET-CT scan before stem cell therapy shows areas in blue color that suggest damage to the brain. These areas are responsible for the social behavior, learning and co-ordination. The PET-CT scan after 8 months of stem cell therapy shows that there was increased brain activity in blue areas suggesting repair of the damage. The PET-CT scan after 18 months of stem cell therapy further progressive improvement in the damaged areas with gain of function seen clinically.

Case 1: On comparing the PET CT scans, it shows increased FDG uptake (indicating improved metabolism and function) in the following areas: superior temporal gyrus, amygdala, fusiform gyrus (social brain) bilateral frontal, temporal, parietal and occipital lobes, bilateral cerebellar lobes, bilateral basal ganglia, hippocampus and parahippocampus. These changes correlate with reduction in hyperactivity, improved cognition, color concepts, social interaction, and awareness about surroundings, phonation, and communication using non verbal means/gestures. Changes in objective assessment scales, such as, WeeFIM (From 58 to 65) and ISAA from 123 to 103) was also seen in the same child.

Case 2: On comparing the PET CT scans, there was improved metabolism seen in the following areas: basal ganglia, mesial temporal lobe, hippocampal and parahippocampal, temporo-parietal, parieto occipital and cerebellar white matter. These changes correlated with improvement in sitting tolerance, reduced hyperactivity, reduced aggressive behavior, clear speech and improved command following

PET-CT SCAN OF THE BRAIN BEFORE STEM CELL THERAPY

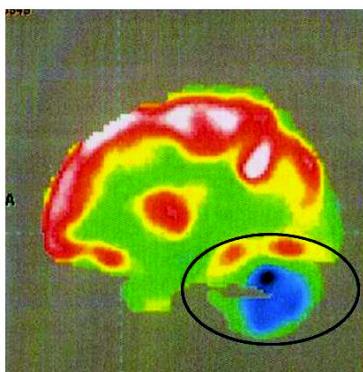
A

Figure A shows the PET-CT scan findings before stem cell therapy. The areas in blue show damaged part of the brain that is responsible for co-ordination of speech and balance.

IMPROVEMENTS AFTER STEM CELL THERAPY

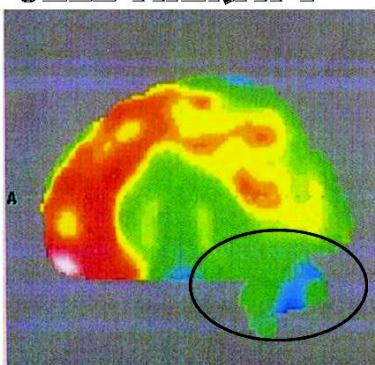
B

Figure B shows the improvement seen after stem cell therapy. Reduction in the blue area suggest repair of the damaged part which corroborates with the improvement in the speech and co-ordination of the child.

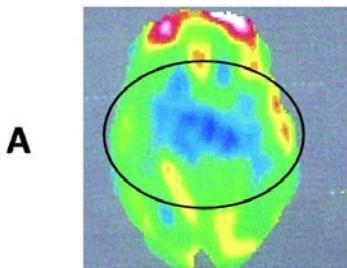
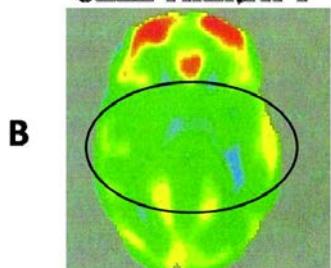
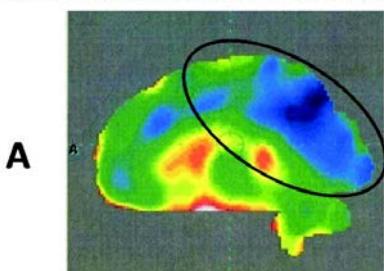
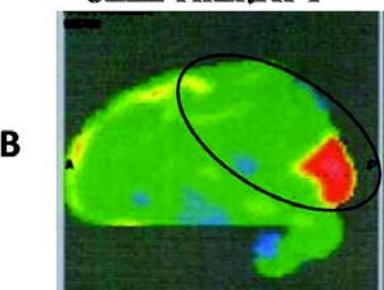
**PET-CT SCAN OF THE BRAIN
BEFORE STEM CELL THERAPY****IMPROVEMENTS AFTER STEM
CELL THERAPY****PET-CT SCAN OF THE BRAIN
BEFORE STEM CELL THERAPY****IMPROVEMENTS AFTER STEM
CELL THERAPY**

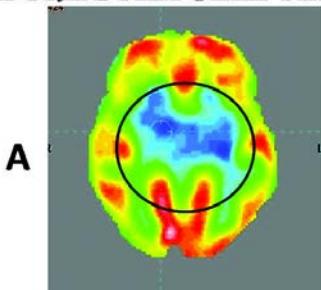
Figure A shows the PET-CT scan findings before stem cell therapy. The areas in blue show damaged part of the brain that is responsible for cognitive development, comprehension and emotional expression.

Figure B shows the improvement seen after stem cell therapy. Reduction in the blue area suggest repair of the damaged part which corroborates with the improvement in learning.

Figure A shows the PET-CT scan findings before stem cell therapy. The areas in blue show damaged part of the brain.

Figure B shows the improvement seen after stem cell therapy. Absence of the blue area suggests complete resolution of the brain damage. Areas in green suggest normal metabolism of the brain.

PET-CT SCAN OF THE BRAIN BEFORE STEM CELL THERAPY



IMPROVEMENTS AFTER STEM CELL THERAPY

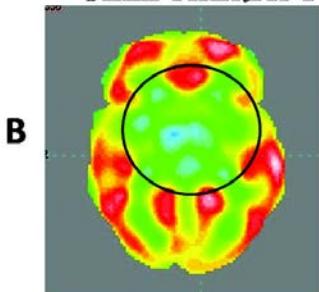


Figure A shows the PET-CT scan findings before stem cell therapy. Damaged part of the brain are seen in blue color.

Figure B shows the improvement seen after stem cell therapy. Absence of the blue area suggests almost complete resolution of the brain damage.

Case reports

Case report 1. Boy with Autism helps tutor his younger sister and her friends with their daily homework post Stem Cell Therapy.

Master S.D is a known case of Autism with ADHD with a history of poor social interaction, hyperactivity and an absence of emotional behaviors. From the time he was an infant, his parents noticed that S.D was not talking nor playing like other children of his age. He would often keep to himself and wandered aimlessly in the house. It was like he was living in a different world. He would engage in self injurious behavior like scratching his skin excessively, socially unacceptable behaviors (touching his private parts) and exhibit aggressiveness. He had poor concentration and attention span and even a small change in his daily routine would make him extremely hyperactive and aggressive. He displayed no emotional bond with his younger sister and would often get violent towards her in the absence of his parents. Even when his schooling began he would be aloof and not interact with other kids. His teachers would complain of his lack of interest and response to class activities. They began to realize that their son was not behaving like kids his age and started approaching doctors for the same. After several visits to a string of doctors, at the age of 6 S.D was diagnosed with 'Autism.' There was no effect of schooling on his social behavior, interaction and expression. At age 14, his parents were finding it difficult to tackle his aggressive behavior. Their

worries kept on increasing as the days went by.

S.D was enrolled into a special school that would help to groom him and train him to live an independent life

S.D underwent Stem Cell Therapy for the first time on 17th May 2011 at NeuroGen Brain and Spine Institute. Before undergoing the therapy, a few pre-operative investigations were carried out. Investigative procedures like PET- CT scan and MRI of brain were done before the treatment procedure. PET-CT (brain) showed moderately reduced metabolic activity in right Broca's, insula, lateral temporal pole, both basal ganglia and left medial prefrontal areas. There was mildly reduced metabolic activity in the right side of the parietal, sensory motor and Wernicke's areas. These were correlated to his clinical features. MRI (brain) was reported normal. On the Indian Scale for Assessment of Autism he scored 81 which confirmed a mild degree of Autism. Functionally he needed moderate assistance for all his activities of daily living. This was measured on Functional Independence Measure (FIM), on which he scored 87 out of 126.

Along with stem cell therapy he was put on an extensive rehabilitation programme. The rehabilitation program was customized in a manner such that it benefits him to the maximum limit. The aim of rehabilitation program was to improve his motor performance, to channelize his aggression and to help him develop his vocational skills.

Post stem cell therapy, it was seen that S.D had improved attention and concentration. He was able to solve puzzles independently. In terms of academics, his handwriting, replication and sentence completion improved. A fair reduction in his hyperactivity and aggression was seen. He was also able to understand and respond better to social conversation, making it easier for him to communicate his needs.

S.D came to the institute again after three months for a routine follow up with the doctors where he was evaluated again. Pleased with the improvements seen in their son, his parents decided to go for another session of Stem Cell Therapy. He underwent the therapy again on 30 November, 2011.

After stem cell therapy, his parents observed dramatic changes in S.D. Not only did his social interaction and communication improve, but he also started exhibiting interest in music, dance and related activities. His overall cognition, understanding and responsive skills improved by over 50%. His speech and language also improved, wherein he started an attempt to use the English language as opposed to earlier times, when he communicated only in his mother tongue. Improvements in his command follow, recognition and fine motor skills were also seen.

Now he interacts with children of his age and actively plays with them. His academic performance was also improving. He has cleared his 8th grade at the National Open School exams and is now preparing for his 10th standard examinations out of which he has already cleared two subjects. His score on Indian Scale for Assessment of Autism reduced from 81 to 51 this nearly touches the "no autism" category. In his daily living activities he became increasingly independent. His score on Functional Independence

Measure (FIM) increased from 87 to 111 as he is independent for all his ADLs. He helps his mother in household work like cutting vegetables, making tea, folding clothes and can even make his favourite maggi noodles independently. The bond with his younger sister has increased considerably. He walks his little sister to the bus stop everyday and even goes to pick her up after school. After 6 months, the PET-CT scan of the brain was repeated, which was compared to the previous report. The post stem cell therapy treatment PET CT scan reports showed improvements in the abnormalities seen earlier specially in the right insula and calcarine cortex, left medial pre-frontal cortex and bilateral frontoparietal lobes. Changes on the PET -CT scan of brain were correlated with his clinical improvements.

Currently, S.D is being home schooled by his mother. Along with his own lesson, he now helps his mother tutor visually impaired and mute children at home, which is a miracle in itself.

Case report 2. I feel so proud every time my daughter returns home with a star stuck to her uniform for good behavior," saysa mother of a 10 year old girl with Autism.

V.T is a known case of Autism diagnosed at age 6. V.T exhibited slow signs of development ever since birth. Even by the age of three, she was yet to utter her first word. As she started growing up, the problems faced by V.T only increased. She made no eye contact with anyone, had poor social interaction skills, did not respond to sound and was extremely hyperactivity and aggressive. She also demonstrated stereotypical and self injurious behavior like hand flapping and head banging. In spite of undergoing regular speech therapy, she was yet to indulge in proper conversation. Due to these behavioral issues, V.T was completely dependent on her mother for all Activities of Daily Living (ADLs). This troubled her parents and they began to see a couple of doctors to understand what exactly was happening to their daughter. A few of them told them that V.T was a case of mental retardation and that eventually everything would be fine. But they were not satisfied with the diagnosis made. They then travelled to Mumbai to see a neurosurgeon with the hopes that finally we would have an answer to all our questions. It was he who informed them that V.T displayed classic features of Autism.

As parents, they were shocked and upset to hear about Autism and that their daughter was diagnosed with Autism.

V.T r underwent Stem Cell Therapy on 24th June, 2013 at NeuroGen Brain and Spine Institute. On examination, it was found was that she had poor eye contact, poor communication skills, was hyperactive, speech was absent, exhibited self stimulatory behavior and was able to follow very simple command. Along with stem cell therapy, she also underwent an extensive rehabilitation program under the care and the guidance of the best experts in the field. She was given carefully designed sessions of speech therapy, occupational therapy, psychological intervention and physiotherapy to help her improve on her skills, abilities and overall development.

After stem cell therapy, her parents observed that her hyperactivity and restlessness

reduced significantly. Another major improvement seen was her response to sound, which was lacking initially. Her sitting tolerance and concentration also improved.

On seeing the improvements in their daughter, her parents decided to go for a second session of the stem cell therapy on 4th June, 2014. Post stem cell therapy, V.T has started developing social skills. Her understanding, cognition and responses have also improved. She now chooses her own clothes, toys and games she desires to play with. She is now showing an interest in learning new skills at her school. Initially, she consumed only soft foods and had poor eating patterns. Post stem cell therapy, she has now started taking in semi solid foods. Her functional independence measure has increased from 53 to 55. She can perform daily tasks like brushing teeth, changing clothes, having meals with minimal assistance.

Currently, V.T is attending Karuna Special School in Nasik. She actively participates in all school activities. Her teachers often compliment her on her good work and attention.

It is a great honour for her parents, when V.T returns home from school with a glittery star on her uniform for her active participation and good behavior.

PET-CT SCAN OF THE BRAIN BEFORE STEM CELL THERAPY

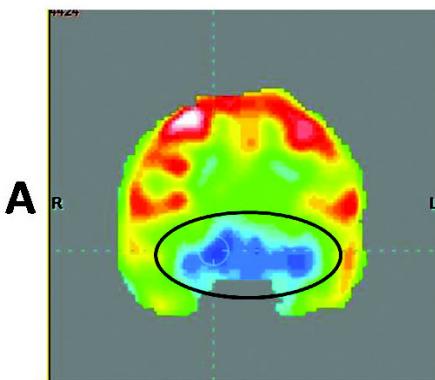


Figure A shows the PET-CT scan findings before stem cell therapy. The areas in blue show damaged part of the brain responsible for social behavior.

IMPROVEMENTS AFTER STEM CELL THERAPY

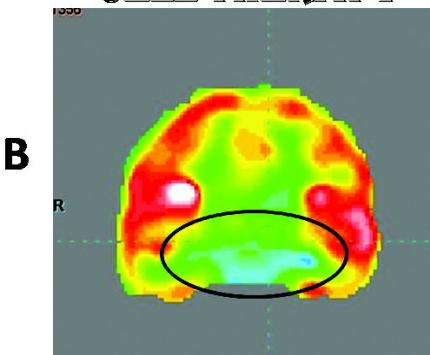


Figure B shows the improvement seen after stem cell therapy. Reduction in the blue area suggests near complete resolution of the brain damage which correlate with the improvement in social relationships of the child.

Case report 3.After several long years of a challenging journey, a mother finds hope for her son in Stem Cell Therapy.

Master A.P,a 20 years, old individual with Autism. As an infant, his parents noted that he was an extremely hyper child and didn't like to sit for long periods. Also, A.P did not develop any speech unlike other children his age. With increase in age he started showing poor oromotor development, disturbed sleep patterns, poor speech, clumsy posture, clumsy hand functions, poor attention and concentration, poor peer relation, poor social interaction, poor communication, poor perceptual and cognitive skills.

Inspite of being physically fit, his behavioral problems was causing a reason of worry for his parents. They met a couple of doctors and finally a child specialist informed them that A.P was an autistic child. This was a disturbing piece of new for them as they were completely unaware of the term 'autism.'

A.P was then advised to undergo speech therapy, psychological counseling and occupational therapy by his doctor. His parents also enrolled him in a special school to help his overall development. Although, there were some improvements, his parents were not truly satisfied with the results. Speech continued to remain absent except for a few murmuring and A.P did not display any interest in other activities like poetry recitation and writing.

A.P underwent Stem Cell Therapy at NeuroGen Brain and Spine Institute on 24th July 2014. Along with Stem Cell Therapy, we also underwent an extensive rehabilitation program under the care and the guidance of the best experts in the field. He was given carefully designed sessions of speech therapy, occupational therapy, psychological intervention and physiotherapy to help him improve on his skills, abilities and overall development.

The happiest moment for his parents, after stem cell therapy, was when A.P said "Khana Khaaya" ("I ate my lunch") merely two days after stem cell therapy without stammering and in a clear tone. His overall attention and concentration has improved and he doesn't get distracted like before. His command following and understanding improved. He now responds to the instructions given to him in school with a new vigor and takes an active interest in the assignments given to him. He can sit for longer hours with increased tolerance and patience. Earlier, it was impossible for him to sit in one place for more than 10 mins. In terms of his academics, he now tries to multi task and learns new activities. His memory also improved. The biggest improvement for him so far has been in terms of speech development. He now recites 1-10 and the alphabet (A-Z) which he was unable to do earlier. He has also started developing an understanding towards relationships. He now reciprocates when his parents ask him questions. This in itself, is a greatest joy for them.

At present, A.P continues to attend his special school and also goes for regular counseling sessions. His parents are extremely happy with his improvements and continue to provide all he care and support that he needs for his further growth.

Case report 4. Stem cell therapy gives Hope to parents for their child's future

Master V.S. was diagnosed with Autism at 2½ years of age when parents noticed delayed speech and hyperactivity. They admitted him to special school at 4 and half years of age. As his sitting tolerance got better, they shifted him to a mainstream school. When at 6 years of age his behavioral problems persisted his parents' concern increased. Aggressiveness, hyperactivity, poor eye contact, repetitive movements and tactile issues were his problems. He feared climbing stairs and jumping. All this made it difficult for his parents to handle V.S. outside the realms of their home.

A repeat consultation with a doctor resulted in getting an MRI done which showed mild atrophy of the right hippocampus. He was on regular speech therapy and occupational therapy, since. They tried their best efforts to help their son but the results were not satisfactory. On learning about Stem Cell Therapy and after seeing the changes in other children treated at NeuroGen BSI, they decided to try it for their child. Before the treatment, a PET-CT scan (brain) was done which showed decreased metabolism of the medial temporal region which was responsible for memory functions. We rated the Indian Scale for Assessment of Autism, on which he scored 130 which identified moderate Autism.

Master V.S. underwent stem cell therapy at NeuroGen Brain and Spine Institute for the first time on 16th July, 2012. Along with stem cell therapy, he was given well planned sessions of occupational therapy, psychological assessments and speech and language therapy. The main aim of rehabilitation was to work on the fears and the behavioral problems that V.S. faced in his daily life. Immediately post stem cell therapy, his parents noted that his eye contact improved and he was now more aware about his surroundings. He had also started imitating words and actions, making it easier for him to learn new activities. He had also exhibited more co-operations during his various therapy sessions. On noticing the positive changes in their son, his parents decided to undergo the treatment yet another time.

After the second session, his ISAA score reduced from 130 to 107. Percentage of disability reduced from 80% to 70% and his Wee FIM score improved from 62 to 68. His parents noticed several other improvements in V.S. His attention span improved. He grasped the pen more appropriately while writing and his eye hand coordination improved. He was thus able to stay within the lines while coloring. At school, he was able to recognize different animals, shapes and colors. Putting his hands and objects in his mouth has reduced completely. He participates in sport activities and can hang on the trapeze for 10 mins. His memory and recollection has improved. Now, he follows all commands such as "bring me the water jug", "put on your sandal", etc. Previously crossing the road with him was a daunting task for the parents as he was very fearful of speeding cars. He now understands how to handle himself and be cautious. Social interaction, eye contact, and playing with children are now more appropriate.

At home, he enjoys spending time with his parents. His interactions with his sister have improved. He does not get aggressive over minor issues and attempts to handle situations independently. He expresses his need to interact and play with other children.

His awareness about his surroundings and recollection of places has improved too. Activities of Daily Living like bathing, brushing, washing hands after meals, which previously required assistance, can now be undertaken by V.S with ease.

He is also very co-operative during all therapy sessions. Stem Cell Therapy gave Master Vaibhav Salunkhe's parents hope for their child's future.

Case report 5 : A ray of hope after 13yrs for young boy diagnosed with Autism

Master A.k. is a 13 year old male and a known case of Autism. He was a full term normal delivery, with history of delayed cry and no neonatal complications. His motor milestones were normal but his speech development was delayed (i.e.) monosyllables developed by 4 years of age. When he was 2 years old, observed his parents, he would play by himself, would make sounds, had repetitive behavior, was hyperactive and had no eye contact. Hence they consulted a psychiatrist who diagnosed him to have Autistic features.

The chief complaints noted down by his parents were his behavioral problems and lack of awareness to his surroundings. A.k. displayed a presence of hyperactivity and aggressiveness, poor eye contact and poor command following. He was also accustomed to throwing temper tantrums. His sitting tolerance was extremely poor leading to severe restlessness. He also displayed stereotypical behavior like rocking and hand flapping. Due to his poor social interaction and communication, he was unable to communicate his needs to his parents. Due to the said troubles, he was dependent on his mother for all his activities of daily living. This was becoming a major concern for his parents, who were worried about their son's future.

His parents tried their level best to integrate A.k into society by enrolling him into a normal school with the assistance of a shadow teacher. Along with normal schooling, they also sent him to a vocational centre where he was given sessions of speech and occupational therapy. Although, improvements were seen, they were not maintained for a long time period. As he grew older, the problems with his behavior went on increasing, making it difficult for his teachers to handle him at school. His parents then enrolled him into a special school/ hostel basis for a year. But his behavioral problems only increased.

Master A.k underwent stem cell therapy on 15th October 2015, at NeuroGen Brain and Spine Institute. Prior to admission, he underwent a series of pre -operative investigations such as MRI, EEG, PET-CT Scan to understand the morphological and physiological abnormalities in his brain structure if any. Along with that, he was also assessed on different scales to get a complete picture about his condition. On evaluation, his functional independence measure (FIM) score was 82 and his ISAA score was 85 putting him in the mild autism category. His Childhood Autism Rating Scale (CARS) score was found to be 30 which indicated mild autism. His PET-CT Scan showed reduced FDG uptake is seen in the mesial temporal structures and left cerebellar hemisphere. Reduced FDG uptake is seen in bilateral basal ganglia. In the mesial temporal structures

there is reduced FDG uptake which is seen in the para hippocampal gyrus, and bilateral hippocampus.

Along with stem cell therapy he was put on an extensive rehabilitation programme. The rehabilitation program was customized in a manner such that it benefits him to the maximum limit. The aim of rehabilitation program was to improve his motor performance, to channelize his aggression and to help him develop his vocational skills.

After stem cell therapy, Master A.k showed several improvements in his behavior and social interaction. His eye contact has improved drastically. He is now able to reach out to people and initiate conversations with them. Not only, does he participate in conversations, he is also able to sustain those for an extended time frame, which he was unable to do earlier. His overall hyperactivity and aggression has reduced and his attention span and concentration has increased. He has also started attending school with the assistance of a shadow teacher. Besides, he's now able to pick up newer skills with ease. At school, he can interact with a group of his teachers and students, participates in art and other vocational activities. Off lately, he has also started practicing yoga at home. His parents have observed that maximum improvements in his social communication and behavior are seen.

Case report 6 :Autistic child from London, U.K. improves after stem cell therapy

Master L.V, 9 year old, child from London, is a known case of autism.

He had a history of normal milestone development, with well developed speech and spoke words like 'pasta', 'biscuit', 'juice'. He was a bright kid and had a good grasping power. But later at 2 and a half years he regressed and his parents started noticing that he had poor social interaction along with regression in speech. They then consulted a psychiatrist and Leo was diagnosed as a case of Autism at the age of 4 and a half years. Since then he was going to a normal school with a shadow teacher, later at 6 and a half years he was sent to a special school and received regular Occupational Therapy and Speech Therapy once a week . His mother was well aware about his problems and always tried all possible treatment options for him.

With confidence in the doctors and faith in themselves, L.V has undergone Stem cell therapy twice, first on 1st October 2013 and yet another session on 15th April 2014.A detailed assessment and evaluation for L.V. was carried out on admission at NeuroGen Brain and Spine Institute. The chief complains as presented by the mother during the time of evaluation were as follows : Poor social interaction, fleeting eye contact, inappropriate emotional responses like irrelevant laughing and crying without any reason, motor mannerisms like finger fidgeting, rocking etc. smelling objects, presence of unusual noises, fearful of loud noises, weak fine motor skills, poor - fair perceptual and cognitive skills.

Functionally he was independent for almost all his Activities of Daily living but the main concern of the mother which she emphasized even during the evaluation was, he

had difficulty in buttoning, zipping and lacing. His functional independence Measure Score was 74.

On assessment he scored 117 (70%) on ISAA {Indian Scale for Assessment of Autism} and 34 on Childhood Assessment Rating Scale.

After stem cell therapy, his parents noticed an overall improvement in his perceptual and cognitive skills including meaningful eye contact, increased attention and concentration, and increased awareness of his surroundings. He started learning new skills like swinging on his own, pointing out body parts correctly, recognizing alphabets A-Z, identifying colors and shapes. He exhibited improvements in his sensory problems and his auditory hypersensitivity has reduced considerably. His parents report that his mannerisms in public places is much better than before, as he no co-operates with them and follows instructions given to him. L.V. has also shown improvements in his social interaction and communication skills. He now plays games with his parents and his therapist in a group; where earlier he was completely aloof. Off lately, he has also started participating in conversations with his relatives and has developed recognition towards them. Whenever he requires something to be done, he draws attention towards himself by vocalizing instead of throwing temper tantrums as before. Besides, he is now trying his level best to be more independent in activities of daily living. He has learnt to button and unbutton his shirt, he can tie his own shoe laces and makes attempts to eat independently at meal times. He now folds his own clothes and places them neatly on the shelves as taught to him by his father. He carries out his routine activities like washing his face, washing hands after meals, brushing his teeth etc with minimal assistance. He has shown an imminent interest in roller skating and his mother has started taking him to skating lessons where he practices for an hour with his instructor. The fact that he listens to the command and follows instructions of someone beside his parents, is a major improvement in itself and stresses on his improvement at cognition, understanding and social interaction. The parent's are very happy with the improvements and are in regular contact with all the professionals at NeuroGen Brain and Spine Institute through email.

Recently they sent a mail saying, "he is doing well (some days more, some less). I am following all your commands :-)... Zipping up is complete since we arrived. 5 colors threading and sequencing is also complete. Buttoning is good. Making straight lines vertically and horizontally without a ruler! He is holding the pen firmly and trying to write the letter O. He is also trying to colour inside the shapes without play dough. It is ok for now, still to be perfect. I am struggling to teach him to tie the shoes lace, but I am taking it easy. Slowly we'll get there. I keep taking him to roller-skating (he skates so well). Today was his first ice-skating lesson and he did quite well. Tomorrow I am taking him to swimming lesson; in the mean time I am trying to organize different play groups (art and craft etc)."

Case report 7 : Special Educator turns to Stem Cell Therapy for her 22

year old Autistic son.

Master S.N, 22, is a known case of Autism, with complaints of destructive behavior, poor speech, poor sitting tolerance, lack of attention and communication. His mother Mrs N, being a special educator herself, noticed increased hyperactivity in her son when he was a mere 3 ½ years. Finally at 5 ½ years he was diagnosed to have Autism and severe mental retardation by a psychologist.

As S.N. grew older, his mother observed that his social awareness and interaction was poor. Although, he didn't mind being surrounded with people, he had difficulty in engaging in conversation with people. He also had poor attention and concentration, poor imitation skills and understanding, poor social responses, poor eye contact and displayed signs of echolalia. With age he became increasingly hyperactive and aggressive and a minor change in his routine would cause him to throw a temper tantrum. In spite of being on regular therapy, under the guidance of his mother, he still displayed behavioral issues causing a reason of concern for his parents.

Master S.N. underwent Stem Cell Therapy at NeuroGen Brain and Spine Institute on 26 July 2014. A complete evaluation was first carried out to get a better understanding of his present status. On assessment, his Functional Independence Measure (FIM) score was 73 and his Indian Scale of Autism Assessment (ISAA) score was 112, suggestive of mild to moderate Autism. On the Childhood Autism Rating Scale (CARS) he exhibited a score of 36, which indicated moderate autism.

Along with stem cell therapy he was put on an extensive rehabilitation programme. The rehabilitation program was customized in a manner such that it benefits him to the maximum limit. The aim of rehabilitation program was to improve his motor performance, to channelize his aggression and to help him develop his vocational skills.

Even prior to Stem Cell Therapy, S.N. was already undergoing various therapy sessions. Post stem cell therapy, reports his mother, his performance in the therapy sessions has improved. His sitting tolerance and attention has improved. Previously, he used to indulge in self injurious behavior like head banging, the frequency of which has reduced drastically post SCT. In terms of social interaction, his eye contact is better than before, he tries to initiate conversation and his imitation skills have improved. He helps the house help in carrying out small activities like fetching spoons, plates and table mats. When earlier, we was unable to fold a handkerchief also, he now helps his mother fold blankets. His memory and command following has also bettered as compared to before. He is now able to convey his basic needs with ease. His parents report that his communication and understanding skills are showing a positive growth.

Having faith in herself and her son, Mrs N, who has been working with children with autism from the past 23 years, has been able to achieve the milestones for her son she always desired to.

29.3 A special discussion

The Dilemma, The Debate, Suggestions

The Dilemma

A major dilemma being faced nowadays by parents and patients of Autism spectrum disorders (ASD) is as to whether they should consider Stem Cell therapy as a treatment option. On one hand, they are flooded with information on stem cells through the press, media, internet, etc and on the other hand they are told by their primary doctors that this treatment is still unproven or that it does not work, etc. These diametrically opposite views create a lot of confusion and conflict in the minds of the patients and their families. The fundamental questions that arise in the minds of parents and patients are:

- Does Stem cell therapy really work for Autism?
- Are there any dangers or risks of doing this therapy?
- What improvements are likely to be seen in the patients with this therapy?
- How do I chose a good center for stem cell therapy and how do I know for sure whether the center I have chosen for stem cell therapy is working to high professional, medical, scientific and ethical standards ?

The Debate

There are two sides to this debate and we shall address both.

- **Point of view - 1 -** For (reasonable view): That Stem cell therapy is safe and works in Autism in terms of functional improvements and helping to integrate the child into the mainstream.
- **Point of View - 2 -** Against (reasonable view): That Stem cell therapy is not a proven treatment and we are not sure that it works. Even if it works, the effects regress or it may also lead to regression in the child's development.

In an extreme form these two above points of view sometimes get expressed as:

- **Point of View 1-** For (extreme view):- Stem cell therapy is a definitive cure for Autism
- **Point of view 2 -** Against (extreme view):- Stem cell therapy is a dangerous, banned and unethical form of treatment.

We believe that it is important to listen to, read about and discuss all the points of view before we finally subject our children to any treatment that is new.

Let's first look at the:

- **Reasonable Point of view -1** (or Stem cell therapy): Which is that Stem cell therapy is safe and works in ASD patients in terms of functional improvements and slowing down/halting the disease progression.

For the above:

Is Stem cell therapy safe?

To understand this we must first realize that stem cells are not one single entity. This has been discussed earlier in this chapter.

There are broadly speaking three different types of stem cells. These are embryonic stem cells, umbilical cord derived stem cells and adult stem cells. Whereas, it is true that embryonic stem cells are potentially dangerous (due to the possibility of their forming tumors called teratomas) and have various ethical issues associated with them , umbilical cord and adult stem cells are not dangerous in any way (there is no risk of tumor formation with them) and are not associated with any major ethical issues. It is the lack of understanding the fact that there are different types of stem cells and that the risks associated with one are not applicable to the other is what creates a lot of confusion.

There are several scientific publications to show that umbilical cord and adult stem cells are safe. In fact a review of all the publications based on these show that there are virtually no major adverse events reported that are connected to these types of stem cells. Based on all the scientific literature and our own clinical experience we can say with a reasonable surety that adult stem cell therapy is safe and without any major or significant risk factors.

Is Stem cell therapy effective for autism?

Regarding the effectiveness of stem cell therapy in autism, we have already discussed about our experience in over 150 children/individuals with autism.

We have used bone marrow derived autologous adult stem cells which were injected intrathecally. Earlier in this chapter some details of these results are given of 150 patients. Broadly, reduction in abnormal behavior and hyperactivity was observed consistently in almost all the patients. Overall improved eye contact, increased attention span resulting in enhanced school performance, improved speech, better communication skills and social interaction are other highlights that were observed after stem cell therapy. Reduction in self stimulatory behavior and self mutilation/self injury behavior are other desirable effects that were observed.

Also from an ethical point of view there is a basis for offering this form of therapy.

As per World Medical Associations Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects:

"In the treatment of an individual patient, where proven interventions do not exist or have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, this intervention should subsequently

be made the object of research, designed to evaluate its safety and efficacy. In all cases, new information should be recorded and, where appropriate, made publicly available."

Autism definitely fits into this definition since "proven interventions" do not exist. Therefore, from an ethical point of view, as per the Helsinki declaration, for children with autism, it is appropriate to use stem cell therapy as a medical intervention. With our own clinical experience of 200 patients of autism treated with Stem cells we can say that it definitely helps in "re-establishing health or alleviating suffering". So, despite the fact that as per the principles of evidence based medicine, stem cell therapy is still an unproven treatment but on the basis of the Helsinki declaration it may be used since there are no other proven interventions. If instead of looking at this through the lenses of evidence based medicine, if we look at this it from the lens of practice based medicine then we cannot say that it is an unproven therapy since there is enough clinical evidence to show that stem cell therapy definitely helps.

Counterview: One swan does not make a summer. Just because at one or a few centers there are good results does not make it a standard of care. It will take many more centers to show the same results (preferably with a comparison with controls) before we can accept it as a standard of care.

Now let us look at the other point of view which is:

- **Reasonable point of View 2 (Against Stem Cell therapy):** That Stem cell therapy is not a proven treatment and we are not sure that it works.

For the above:

There is substance to this point of view. Today the practice of Modern medicine is based on what is called "evidence based medicine". For a treatment to become a standard of care it should have been evaluated by multiple centers through what are called prospective, randomized, double blind, placebo controlled studies. This type of evidence is called Level I evidence. At present, we do not have Level I evidence for the role of stem cell therapy in autism. So when your doctor says that this is not yet a proven treatment then based on the principles of evidence based medicine that statement has a basis. By these standards it is also not incorrect for any doctor to say that "we are not sure that it works".

Counter argument: It will take several years (anywhere between 3-7 years) before class I evidence in the form as mentioned above is generated. But till then, these children are growing and have been kept bereft of timely intervention, which has the potential to help them become independent. Japan has recently passed a law, which states that stem cell therapy will be approved even if it demonstrates dramatic effectiveness in pilot studies of as few as ten patients in one study. Hence, the therapy will be available to the patients earlier than before.

Regarding the two extreme views that:

- Stem cell therapy is a definitive cure for autism and
- Stem cell therapy is a dangerous, banned and unethical form of treatment we wish to state that neither is true.

Stem cell therapy does not cure autism. That view or statement is completely incorrect. What it does is that it reduces hyperactivity, improves eye contact and attention span. This overall helps the child become more amenable to be trained. The other aspects, such as social interaction, and cognitive development is also enhanced after stem cell therapy.

The other extreme view is also incorrect. Stem cell therapy (especially with adult stem cells and umbilical cord stem cells) is not dangerous in any way whatsoever. It is also not banned treatment. The confusion of its being banned comes from the fact that in the year 2001, President George Bush of America imposed a ban of the federal governmental funding of embryonic stem cell research. It should be noted that:

- Ban was only for the federal (government) funding of research
- Ban was for embryonic stem cells only and not for adult stem cells

This ban on the "federal funding for embryonic stem cell research" has subsequently been lifted by President Obama as soon as he became President in the year 2008. Different countries have different regulations and guidelines for use of stem cells. In the US the body to approve this is the US FDA. In India the regulatory body for Stem Cell research is the Indian Council of Medical Research. According to its guidelines it has put embryonic stem cells in the restrictive category but adult stem cells and umbilical cord cells are in the permissive category. It is also not unethical to treat individuals with autism with adult stem cells since it falls under the category of diseases for which there is no proven intervention and so as per the Helsinki Declaration an unproven therapy can ethically be used.

We would also like to highlight some statements made in the White paper published by the International Society for Cellular therapy (Gunter, K. C. et al, Cell therapy medical tourism: time for action. Cytotherapy, 12(8), 965-968.

- A] It makes an important distinction between clinical trials and medical innovation "Medical innovation in cellular therapy may be viewed as ethical and legitimate use of nonapproved cell therapy by qualified healthcare professionals in their practice of medicine. Patients not eligible for controlled clinical trials should be able to choose unproven but scientifically validated cell therapy medical innovations, if the researchers are competent and those seeking treatment are truthfully and ethically informed. There is a place for both paradigms in the cell therapy global community"
- B] It also highlights the patients' rights to seek treatments: "Patients seeking medical treatment for cellular therapies have the following rights that must be respected by healthcare providers and all associated with their care. 1. The right to seek treatment: patients and their families/partners have the right to seek treatments for their diseases. No entity should withhold this fundamental right unless there is a high probability of harm to the patients. 2. The right to information: patients have the right to an accurate representation regarding the safety and efficacy record of the cell treatment. This includes probable side-effects and a truthful record of

efficacy. 3. The right to informed consent: patients have a right to a true informed consent process that includes all the elements described above."

- C] It recognizes the "valid compassionate use of unapproved therapies" by classifying centers offering cellular therapies into the following groups.
1. Approved/standard therapies (e.g. hematopoietic stem cell transplant and other cellular therapies approved for marketing)
 2. Controlled clinical trials
 3. Valid compassionate use of unapproved therapies
 4. Treatments not subject to independent scientific and ethical review.
- D] It identifies legitimate cell therapy centers on the following criteria: "The following guidelines are useful in assessing scientific rigor and for differentiating between legitimate cell therapy medical services (including clinical trials and medical innovation) and fraudulent cell therapies.
1. Peer review and transparency: consumers of cell therapy medical innovation should evaluate evidence from peer-reviewed publications, professional society presentations and scientific recognition. They should be encouraged to seek multiple professional opinions and have all questions answered to their satisfaction.
 2. Safety and regulatory history: patients should consider the reputation of the investigator and clinic, as well as the record of disciplinary activities against these entities.
 3. Informed consent: patients should expect to be informed fully and accurately of the risks, benefits, costs, safety, compensation for injury, investigator conflicts of interest and alternative therapies, as a minimum." For a more detailed reading on the two sides of this ethical debate and specifically our views on the subject we refer you to a paper published by Dr. Alok Sharma in the Journal of Neurorestoratology tilted "Rethinking on ethics and regulations in cell therapy as part of Neurorestoratology". This can be downloaded from the website www.dovepress.com

Another aspect that as parents you should be aware of is that Stem cell therapy is presently available in the following ways:

- As part of a clinical trial, where depending on the trial design you may or may not get randomized to either actually getting the stem cell therapy or be part of a control (i.e. receive no treatment) or receive a placebo (i.e. be given something harmless but not actually get stem cells). It's important to understand all aspects of the clinical trial design (including inclusion and exclusion criteria, protocols, materials and methods etc) before enrolling for any clinical trial. The results of all clinical trials are published in scientific journals.
- As part of a therapy, which may be combined with a rehabilitation program or other treatments. Here all the children will receive the Stem cell therapy as there is

no randomization into control groups or placebo groups. This may or may not be a part of a study. Being part of a study means that the clinical, investigative data, improvements and adverse events will be analyzed and the results subsequently published in scientific journals.

Suggestions

Suggestions to help you make decisions about whether to consider stem cell therapy for your autistic child?

Now here are some suggestions on what you should do as parents:

There are two steps to this

Step one:

- To decide whether to undergo stem cell therapy?

Step two:

- If yes then where to undergo the Therapy
- Which type of stem cell therapy to undergo?

Step one: This is a decision that has to be taken by you yourself after understanding all aspects (the pros and cons) of the treatment. We must realize that for every choice we make there are consequences of two types. Good outcomes and not good outcomes. This is true for whether we make a choice to do something and even when we make a choice to not do something. So if we do stem cell therapy there is the possibility of good and not good consequences. A not good consequence could be a lack of improvement or some adverse event. But, if we choose to not do the treatment then too there are good and not good consequences. For example, a not good consequence of not undergoing the treatment is a regression of the child's neurodevelopment. We hope that this book and this chapter in particular equip you with the knowledge to be able to make an informed choice. But the final call will still have to be taken by you.

Step two:

- If yes then where to undergo the Therapy?
- Which type of stem cell therapy to undergo?

Regarding which Stem cell center to take the treatment from our advice would be that you get answers to the following questions when visiting or consulting with a Stem cell therapy:

Question 1: Does this center have an Institutional Ethics committee??

In India it is mandatory to have separate Stem cell ethics committees which are referred to as ICSCRT (Institutional Committee for stem cell research and therapy).

This is important since an ethics committee evaluates sanctions and monitors the work being done at the center. It ensures a system of checks and balances thereby ensuring patient safety.

Question 2: Has this center published their results in peer reviewed scientific journals??

This again differentiates genuine centers working with scientific and academic principles and values from those just set up for commercial purposes. The acceptance of papers for publication entails a process where other doctors and scientists review the data submitted and decide its merits and suitability for publication. This is called peer review and though not a guarantee, it does to some extent ensure that basic scientific and medical principles are being followed for the work that is being published.

Question 3: Is special informed consent being taken??

If yes, you should ask for a copy of the consent and understand it before accepting to undergoing the treatment. As per a Supreme court of India ruling, an informed consent should have the following information [1] Diagnosis, [2] Nature of treatment , [3] Risks involved, [4] Prospects of success , [5] Prognosis if treatment not given, [6] Alternative treatments. In any case these are questions you have the right to ask these from the treating doctors. If the doctors openly and authentically answer all these questions then it is worth considering this center. If the doctors do not give you this information or get upset and angry if you ask questions or are not open and honest about what they do then we recommend that you do not undergo therapy at this center. All this is information that you have a right to and no doctor is doing you a favor by giving it to you.

Question 4: What are the past clinical results of this center with reference to safety and efficacy? What improvements have been noticed in the previous patients treated?

You should understand the improvements reported or published by the center and compare these to your own child and determine whether the symptoms that have been shown to improve are the ones in your own child that you want to see an improvement too. You should specifically enquire about any adverse events both minor and major as well as both short term and long term in the patients that have already been treated.

Question 5: What types of stem cells are being used at the center?

Which type of stem cell therapy to undergo is a very major question?

- With our present state of knowledge we would advice extreme caution in considering embryonic stem cell therapy due to the risk of teratoma formation. It will take a few more years before the safety of embryonic stem cells is completely established.
- Umbilical cord derived cells are definitely safer than embryonic but one should know which company is manufacturing these cells and should obtain some more information on this company. Is it a reliable company and has good manufacturing facilities and practices and has this company taken the necessary regulatory permission and sanctions to manufacture these cells. In India permission is required from the Drug Controller General of India (DGC). If these are in place then it may be alright to consider them.

- However, Adult stem cell taken from the patient's body (autologous) and which have not been manipulated outside the body are the safest of all types of stem cells. Unless there are other compelling reasons, these are the stem cells to be considered first. So in summary our answers to the fundamental questions we started out with at the beginning of this chapter can be answered as follows:

Question: Does Stem cell therapy work for autism?

Answer: Yes, it helps in producing various clinical improvements in the child.

Question: Are there any dangers or risks of the child's condition worsening?

Answer: No worsening in any of the children has been noticed so far.

Question: What improvements are likely to be seen in the patients with this therapy?

Answer: It does help to reduce hyperactivity, improve eye contact, and improve attention span, especially those non-responsive to regular rehabilitation or medication.

Cognitive abilities as well as social interaction, social discrimination has also been seen to improve.

Questions: How do I chose a good center for stem cell therapy and how do I know for sure whether the center I have chosen for stem cell therapy is working to high professional, scientific and ethical standards ?

Answer: Select a center that has an institutional ethics committee, that has published its results in scientific journals, where special informed consent is taken and all your queries are satisfactorily answered, that can show you documented improvements in its earlier treated patients as well as safety data and that is preferably working either with adult stem cells derived from the patient or umbilical cord stem cells obtained from a reliable company.

Conclusion:

1] There is a definitive scientific and medical basis to consider stem cell therapy as a form of treatment for ASD. 2] The published results specially with adult stem cells show excellent safety and good clinical outcomes. The results shown are better than any other form of treatment currently available. 3] It may not be a standard of care at present, but for that to happen will take several years . 4] It is important that parents / patients understand all aspects of the treatment before deciding to have their children / themselves undergo this treatment.

30. Brain Function Training (BFT)

Brain Function Training (BFT)/EEG Biofeedback/ Neurofeedback(NFB),can be defined as a technique in which the brain that are not considered normal with respect to age-related behavior, are "Trained" to improve their functionality. The training imparted is to normalize brain function and thereby behavior that is appropriate to the external occasion. This is done by working with the brain either on the surface or internally with the areas that are not working "normally."

Method :

Brain Function Training (BFT) consists of a set of neurophysiological based methods for modifying brain function, includes EEG-biofeedback (self-regulation) and other modalities such as Biofeedback, Trans-cranial Magnetic Stimulation (rTMS), Direct Current Stimulation (tDCS)and Deep brain stimulation (useful especially in tremor and Parkinson's disease), pulsed Electro-Magnetic Force (pEMF), Brain-computer interface (BCI),and many such bio-medical interventions that are in the pipeline.

Brain Function Training is preceded by an extensive clinical and neuropsychological evaluation. Then a BFA/QEEG is done. In other words, Neuropsychology and BFA/QEEG are very closely related. Both the Quantitative and Qualitative side of assessment when used discriminately provides localization of problem areas and networks in the brain. A BFA/QEEG is a digital version of the EEG recording done in any neurologist. It uses the 10-20 system and uses 19-electrodes. It is different from the normal EEG. It consist of 3 different parts-

1. Eye-ball the EEG trace;
2. Comparing it with a Normative Database;
3. Electrical Imaging.

Advantages of QEEG :

- QEEG condenses data from a standard electroencephalography (EEG) into a single page color-coded summary, which helps neurologistto interpret results at a glance. (This summary is not possible with a regular EEG).

- Excellent resolution with spatial-temporal resolution
- Useful in behavioral neurological organic disorders
- It guides BFT/Neurofeedback therapy

When the experienced clinician at BFT is eye-balling the EEG and finds plausible seizure activity, the best option is for a neurologist/neurophysician to attend to the issue in order to stabilize the brain. Only a stable brain is fit for regaining Health and Wellness. Yet the QEEG happens to give more information to the discerning clinician. For example,

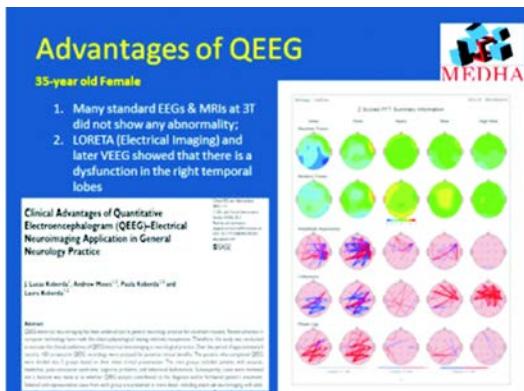


Figure 30.1 : Advantages of QEEG

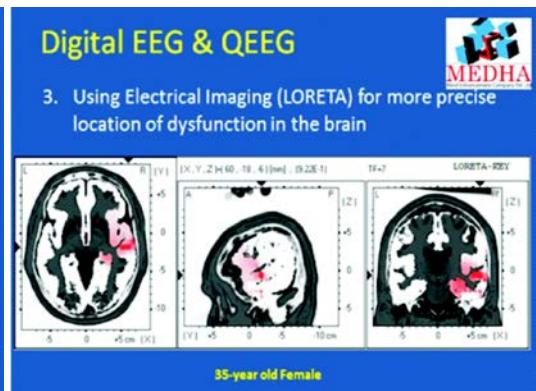


Figure 30.2 : Digital EEG & QEEG

In this case of a 35-year old female, many EEG and MRI at 3T showed no abnormality. Electrical Imaging using BFA/QEEG predicted a plausible dysfunction in the right temporal region including the precise Brodmann Area, in which Frequency and by how many standard deviations. This dysfunction was later confirmed with a VEEG later. Brain Function Training also helped her overcome this issue.

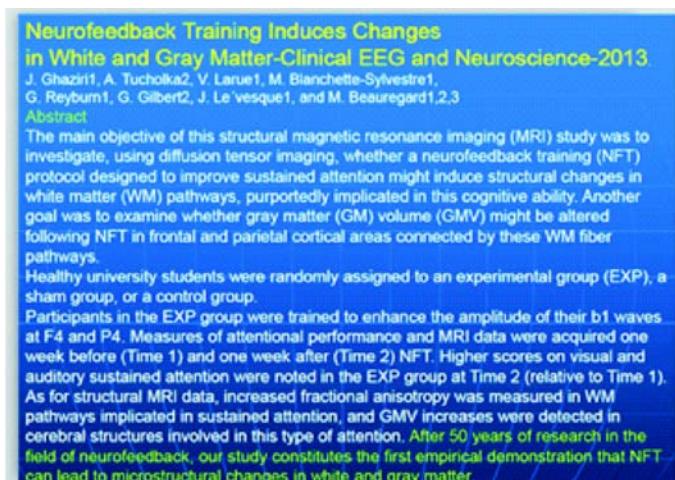


Figure 30.3 : Scientific Paper on Neurofeedback training induced positive changes

Indications :

BFA/QEEG and BFT/NFB are useful not just in Epilepsy; they can be used in Pain Management (for example Migraines), Autism, Mild TBI, ADD/ADHD, LD, Improving Sports performance, Enhancing Learning Skills, Depression, Addiction, and so on. Research work is on-going in Dementia, Alzheimer's. BFT is no silver bullet. It has been found to improve neuroplasticity in the brain. The recent paper Ghazini et all (Clinical EEG & Neuroscience, 2013) provided empirical evidence for the first time that BFT/Neurofeedback induces positive changes in both White matter and Grey matter, thus enabling Neuroplasticity in the brain.

By localizing the dysfunction with respect to loss of Neuroplasticity in the brain using a combination of QEEG and linking observed Clinical symptoms using good clinical neuropsychological interviews; it is possible to provide sustainable results in a very short period of time.

Side Effects of BFT/NFB :

In previous studies, no major side effects have been reported. But few may have some minor unwanted symptoms.

- Fatigue may be experienced by few
- If there is brain injury, one may experience nausea and dizziness.
- Some may also experience irritability.

Factors other than the protocol itself (e.g. some smell in the room), lack of sleep, psychedelic lighting, etc. may trigger seizures. [In our experience of more than 15 years in the field, there has been no case of seizures increasing or occurring at any time. Dr. Barry Sterman discovered how this method of Brain Training helps people with nocturnal seizures & drug refractory seizures. In a meta-analysis conducted by Dr. Sterman (2009) on 174 people, 82% had shown significant improved seizure control (defined as 50% reduction in seizure incidence). 5% of these cases reporting a complete lack of seizures up to 1 year subsequent to completion of training.]

Case Study in Autism:

The 6-year old boy with Autism came to us in May 2014. He exhibited extreme hyperactivity, was emotionally labile, impulsive, no social awareness, very poor comprehension, no social behavior and no speech. His initial BFA looked like this

We did 20 sessions of BFT and the post BFA Map looked like this : (See Next Page)

- Reduction in Cortical Irritability leading to better Attention Capability;
- Reduction in Hyperactivity;
- Less Labile, so less mood swings and tantrums;
- Needed major improvement in basic comprehension to follow commands of caregivers and friends

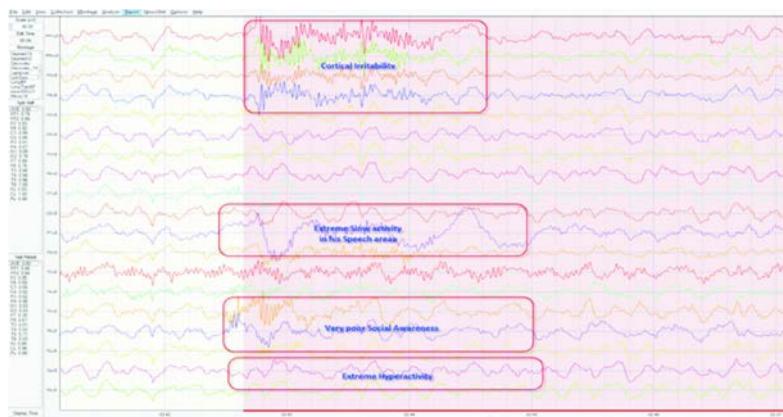


Figure 30.4 : Pre-BFA

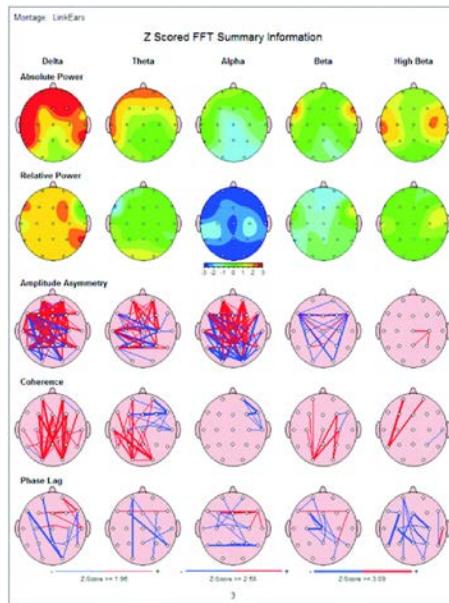


Figure 30.5 : Pre-BFA

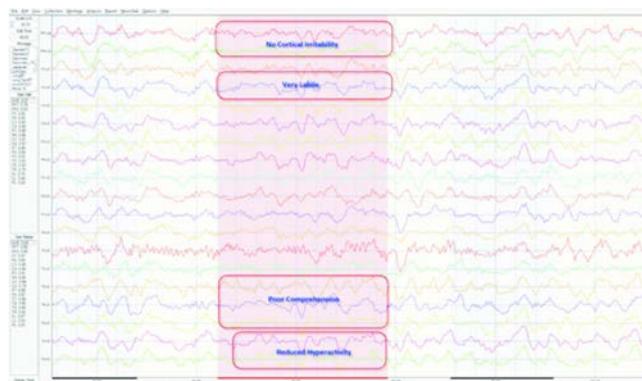


Figure 30.6 : Post - BFA

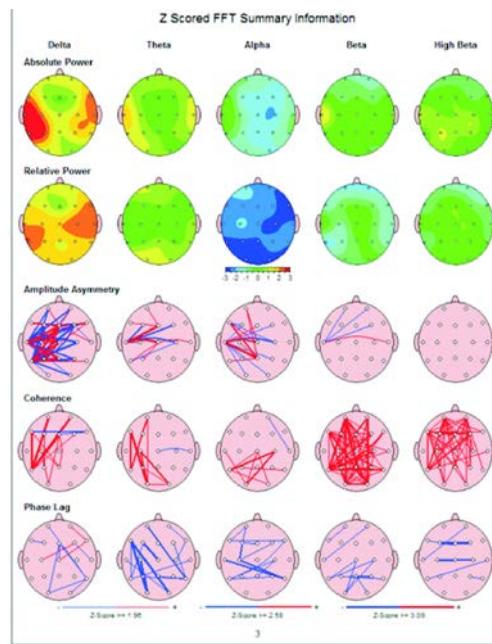


Figure 30.7 : Post - BFA

We have worked with him for more than 12 months now and he is now speaking fluently, but still needs to be prompted. He is very impulsive and a compulsive learner (probably making up for missed opportunities). BFA has helped to in localize the issues. BFT (thrice a week) helped in training dysfunctional areas and reinforcing those that had attained normal functioning. His latest BFA looks like this :

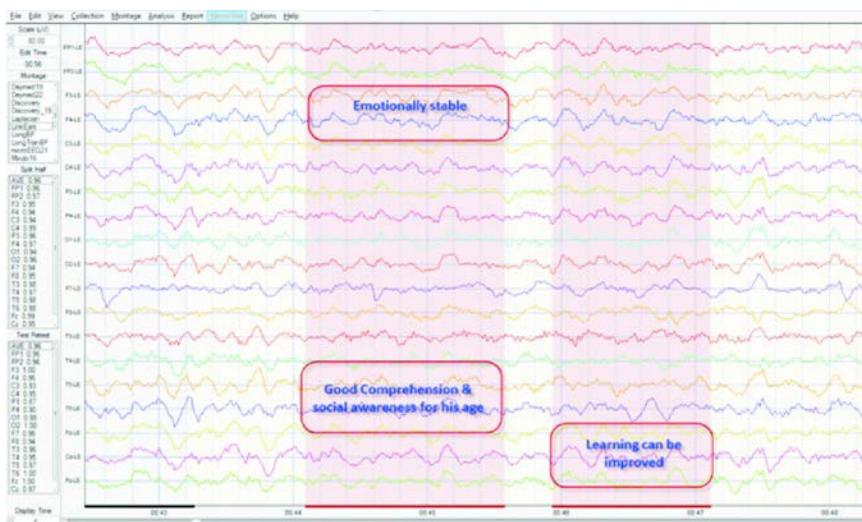


Figure 30.8 : Latest - BFA

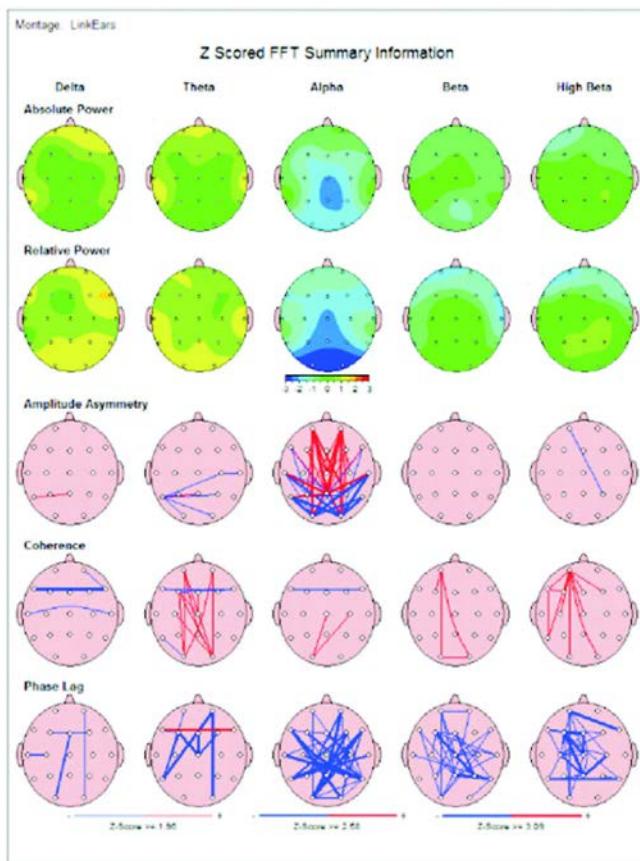


Figure 30.9 : Latest - BFA

BFA helps in developing appropriate protocols that help in localizing the plausible causes to the observed aberrant behavior. BFT retrains and re-engineers the brain to normalize brain function. BFA & BFT together provide a new plausibility for both experienced & budding care providers and hope to parents. BFT can deliver sustainable results in conditions when judiciously combined with all existing methods of trainings for Autism. BFA & BFT are catalysts that exponentially reduce the time needed to enhance brain function. This means the therapist may need to acquire new competencies and skills while also investing in good bio-medical software and hardware. With these tools, they would help people to seek their goals today while setting new paradigms for tomorrow.

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SUMMARY :

Though the mainstay of treatment in autism is currently based on sensori-motor integration, behavioral therapy and speech therapy, medical research continues to explore newer alternatives. Some of these are novel in their approach towards autism. They aim at normalizing, altering or improving functions at the cellular level (neurophysiology, immune hypersensitivity, etc.), which will ultimately result in observable clinical, radiological and functional improvements. The rationales supporting the role of Vitamin B12 therapy, Hyperbaric Oxygen Therapy (HBOT) as well as Stem cell therapy in Autism Spectrum Disorders are being understood better with each passing day. But the great hope for the future for autism is definitely Stem cell therapy. It has shown to produce good clinical and functional improvements along with objective improvements in the various scales. What is most exciting are the improvements being seen on the brain imaging such as SPECT and PET CT scans? What makes these treatment options attractive is the simplicity of the treatments and the lack of any major complications. With the availability of these treatment options, in the very near future Autism will no longer be considered a incurable neurological disorder.



SECTION F

Preparing for the future challenges

31. Schooling for The Child With Autism

Should my child study in regular or special school?

A common dilemma that bothers several parents of children with autism is that of their child's formal education. Due to lack of clear cut guidelines, parents are unable to decide what type of schooling system is best for their child. Currently, the number of schools providing education to children with autism is severely limited as compared to the need. However, the range of services is extremely varied and diverse ranging from autism specific services to mainstream schools. You too must have queries whether your son/ daughter should attend regular school or a special school. This is a tough decision and several factors play a role in it. Also the inconsistency in the governing regulations makes it all the more difficult for you. Unfortunately even today, several parents are denied admission by schools for their kids with autism. This results in many children with autism, not receiving proper formal education. Many parents have them drop out of main stream school as they are unable to cope with the demands. Remember that in India every child has the right to receive basic formal education as enforced by the amended Sarva Shiksha Abhiyan which now includes children with autism too. Hence, in this chapter we attempt to throw some light on the possible options for your child and help you take an informed decision. Consult your therapist or psychologist to help you decide.

Your child may be turning five soon and the school's application deadlines may be nearing. Remember to evaluate your child for preparedness. His chronological age is not the only determinant. Several factors indicate readiness for kindergarten. Match your child's current abilities with the needs of the school he/ she would be attending. Requirements and expectations can be diverse and not every typical child also fulfills all of them. A few of them you may have to consider are that he/ she should be able and willing to:

- Speak clearly or communicate needs in an alternative fashion
- Follow instructions

- Listen actively - if you read him a short picture-book story, can he follow along, then retell it in his own words?
- Interact amicably with other children and with adults: wait her turn, share, refrain from hitting, biting, etc.
- Participate in group activities
- Put on outer garments without assistance
- Use the restroom without assistance
- Manage lunch items (juice boxes, baggies, lunchboxes) without assistance
- Blow nose without assistance
- Handle pencil / markers, scissors
- Count to ten
- Be familiar with the alphabet
- Learn new things, Shows some curiosity about her world
- Identify colors, shapes, body parts (some schools expect a certain level of knowledge in these areas)
- Recognize and respect authority
- Spend extended time away from parents

What are the options available for your child?

Broadly speaking schools may be categorized into the following:

- Mainstream or Regular,
- Inclusive or Integrated,
- Special services schools,
- Home-schooling,
- Residential schools or homes.

1. Mainstream or Regular Schools :

These include the regular government, public and private schools. These schools follow the standard curriculum (ICSE, CBSE, SSC, IB, etc.) and methods of teaching. Few main stream schools admit such children. A basic requirement for many such schools is that the child should be verbal and communicative by the age of 3 to 4 years. Failing this requirement due to delayed speech development unfortunately leaves these children behind. Now with the Right to Education Act being enforced, this scenario may change. The environment in these schools is not specially designed to accommodate a child with autism. High functioning children with

autism or those with Asperger's Syndrome may be able to fit into such set ups. Several schools in India fall into this category where there are several physical, social and environmental barriers to the successful education of a child with autism.

2. Inclusive or Integrated Schooling :

Some schools integrate children with autism into the classroom along with other "typical" children. "Mainstreaming" or "Inclusive education" is a drive that the Department of Education (India) has also taken up seriously over the last few years.

Private schools in India are slowly taking steps towards the initiative of inclusive education. According to Booth and Ainscow, (1998) inclusive education entails "increasing the participation of students in, and reducing their exclusion from, the cultures, curricula and communities of local schools". Some of the strategies that may be taken to aid in inclusion are:

- Making alterations in their curriculum. For example, giving them the choice to study only one language, instead of the otherwise compulsory two.
- Providing extra time of 30 minutes to 1 hour for the exams.
- Allowing the use of calculators for exams.
- Providing a writer for exams or allowing the child to type his answers on a computer, instead of writing them.
- For those with exceptional verbal skills, oral exams could be conducted.
- Lowering the cut off for passing exams to a 30% instead of the standard 40 or 50%.
- Providing a shadow teacher, who would sit beside the child and guide him/her through the lessons taught by the class teacher.
- Allowing a parent to sit with the child in class or stand outside and observe.
- The child's classes may be scheduled based on his capacity. For example, if his sitting tolerance is not sufficient he could attend half-day of school.
- Providing therapy sessions in between classes could be beneficial. Intersperse teaching with sessions of occupational therapy, physical activity, speech therapy and behavioral therapy.
- Provide training to the teaching staff about teaching methods, management techniques.
- Sensitizing the staff, students and parents of the school about autism, the associated problems and ways of dealing with children with autism.
- Reducing the physical, environmental and social barriers that hinder participation of children with autism. For example, replacing the loud disperse bell which a child with autism may be aversive to, with a dull blinking light in the corner of the classroom.
- Providing longer lunch breaks for them to be able to eat by themselves.

There are many more strategies that could be employed by schools to help integrate children with autism into the society. Arbitrarily, children with autism with a minimum IQ of 80 are admitted to such schools. Children with severe autism, who are very hyperactive, aggressive, and absolutely non-communicative or who could potentially harm themselves or other children are not suitable for such methods of schooling. Some children may attend few hours of school each day, after being medicated for reducing their hyperactivity. Schools also set up a support system or team of psychiatrists, clinical psychologists, occupational and speech therapists for the child and his/ her parents. Initiatives are taken to promote special skills of such children, too.

3. Special Services Schools :

This broad category of schools are exclusively designed to cater to the special needs of children with autism and may include children with other conditions such as cerebral palsy, mental retardation, down's syndrome, etc. The curriculum, infrastructure, teaching methods and professionals are specifically chosen to suite the requirements and abilities of these children. These schools admit children who may fall somewhere on the moderate to severe categories of autism. Children with an IQ score of less than 80 are good candidates for these schools. Schools catering to such a population often have their own protocols and methods of functioning. Some of these have been enlisted below.

- Schools affiliated to the National Institute of Open Schooling (NIOS): The National Institute of Open Schooling (NIOS) is the Board of Education for open schools, under the Union Government of India. It is the largest open schooling system in the world that aims at providing sustainable opportunities for learning with universal and flexible access to quality school education and skill development. It offers the following courses:
 - Open Basic Education Program, includes the following levels-
 - OBE 'A' Level Course-Equivalent to class III
 - OBE 'B' Level Course-Equivalent to class V
 - OBE 'C' Level Course-Equivalent to class VIII
 - Secondary Course-Equivalent to class X
 - Senior Secondary Course-Equivalent to class XII
 - Vocational Education Courses
 - Life Enrichment Programs
- Individualized Education Program (IEP) is being increasingly adopted by schools that deal with only Children with Special Needs. Each public school child who receives special education and related services must have an Individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly individualized document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when

appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability.

To create an effective IEP, parents, teachers, other school staff-and often the student-must come together to look closely at the student's unique needs. These individuals pool knowledge, experience, and commitment to design an educational program that will help the student be involved in, and progress in, the general curriculum. The IEP guides the delivery of special education supports and services for the student with a disability. Children are taught individually in a conducive environment. Sometimes children with similar IEPs may be clubbed together in small groups. In countries like the USA this curriculum is used for children with special needs admitted to inclusive / integrated schools.

Schools may follow their own procedures for admission and also design a curriculum and teaching method based on their expertise. Visit schools and discuss with the concerned staffs to be able to choose the best school for your child. Tests and assessments are usually conducted by the school to understand the child's potentials and needs. Some schools may require certification, IQ scores and a diagnosis of autism provided by a Government Hospital. It is the age of your child, autism symptoms severity and IQ level will be considered before a judgment is taken on the type of school your child should go to.

4. Homeschooling :

Though not a well known and widely accepted concept in India, home-schooling is an alternative you could try for your child who is very restless, inattentive or unmanaged by anyone but yourself or a special educator you may employ. This more widely practiced in the Western countries. You may have your child registered to any of the education boards (CBSE, NIOS, SSC, etc.), teach your child the relevant lessons at home and have him/ her appear for the exams privately. The child studies in a protected environment and may learn better. A disadvantage of this is that your child loses out on the opportunity to meet, play or interact with other children. The exposure to social situations will be limited.

5. Residential facilities :

Residential facilities provide for holistic care and education of children with autism. Again these children may be clubbed with children having similar neurological or developmental problems. A team of trained professionals are employed to take care of these children in a protective and nurturing environment. The child lives away from his/ her parents and may visit home only few times a year. Provisions for staying and food are provided. The child may be provided with training for daily living skills, social skills, behavior modification, and vocation and hobby development. It is necessary that you choose an established and reliable institute for your child. Regular monitoring of your child is necessary. Parents choose such an option when the child's behaviors are out of hand and they are unable to train

or handle him/ her. Discuss about this option with your therapist or psychologist before taking a decision.

The efforts to increase early diagnosis coupled with the rise in number of qualified special teachers, professionals and setting up of appropriately equipped regular schools is paving the way for early educational and behavioral interventions, enabling the child to make significant gains. The age of your child, IQ score and severity of symptoms severity are factors that decide the type of school your child should go to. Basic formal education is not only necessary but is also their right. It provides a base for their integration into our society.

- Provisions offered by Indian Education Boards ICSE (Indian Certificate of Secondary Education) Board

The ICSE Board selectively grants the following provisions as per the specific needs of individual students:

- Extra time - 15 minute/ per hour or 25% of total time extra.
- Exemption from 2nd language: student need not take another subject in lieu.
- Use of calculator in some cases for mathematics.
- Question Paper will be read out to the student.
- Use of a writer, if required, as per the rules.

How to apply for provisions?

The School Principal should forward a detailed Psycho educational assessment by a recognized Professional or institution to the ICSE Board, specifying the area of difficulty and the type of support required for the candidate to satisfactorily complete exam papers.

- CBSE Board Central Board of Secondary Education (CBSE) allows for the following accommodations for students with autism:
 - Permitted use of an amanuensis (a writer or typist)
 - Additional time as given below:
 - For paper of 3 hours duration 60 minutes
 - For paper of 2½ hours duration 50 minutes
 - For paper of 2 hours duration 40 minutes
 - For paper of 1½ hours duration 30 minutes

Option of studying one compulsory language as against two. This language should be in consonance with the overall spirit of the Three Language Formula prescribed by the Board. Besides one language any four of the following subjects would be offered - Mathematics, Science, Social Science, another language, Music, Painting, Home Science, Introductory Information Technology, Commerce (Elements of Business) & Commerce (Elements of Book Keeping and Accountancy)

How to apply for provisions?

Head of the Institution needs to issue a certificate of school based evaluation covering the past 10 years' academic record.

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32. Tips For Teachers

Teachers play a crucial and a major role in the education of children with autism. This is because these children spend half of their time in school. Thus it is imperative for teachers and educators to be aware of autism, its characteristics, the difficulties faced by these children and the strategies which they should be well equipped with, to deal with them. Teachers can make a huge difference in the lives of children with autism, as they are the guides for them at school and they lay a strong foundation for the children.

Here we provide you with a list of techniques you could employ to help your student attend to lessons, grasp them and function well in the school environment alongside other "typical" children. With the aim of inclusive education for children with autism in main stream schools, these following points must be incorporated in your everyday teaching.

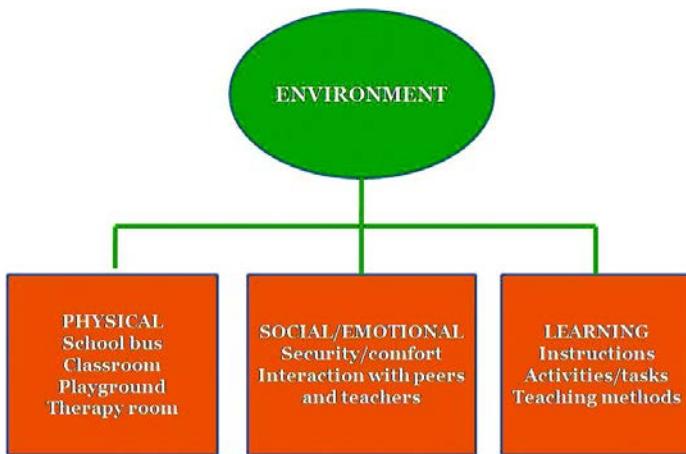


Figure 32.1: Productive School Environment

As a teacher you first need to be aware of the condition i.e., autism. Understanding what autism is, its features and the problems these children have would be of immense helpful to the teachers. Gaining sufficient information and closely interacting with these children to understand the real problems would help you formulate an effective teaching plan for the child.

Getting to know the child better would mean that you not only know his deficits and needs, but also his strengths and areas of interest. Note down the following information:

- Strengths and interests
- Situations leading to, fear, frustration or stress
- The areas that need to be worked on
- Learning style or preferences

Well defined clear and specific goals for the child need to be developed for the year or the semester. Design your weekly plan by keeping in mind the abilities of these children.

Once the goals have been clearly listed they need to be communicated to the others in the team like the occupational therapist or the remedial educator, etc. A team effort would help maximize the outcomes.

Continuous interaction with the parents is essential. Keep them updated about the child's performance and discuss how they should go about with teaching at home. Learn some strategies from parents that have been identified to work best with the child.

It is necessary to sensitize other children in the class and school. Conduct small lectures and demonstrations to educate other children about autism, the problems related to this condition and ways of effectively dealing with these individuals. Ensure that no instances of teasing, bullying or ill treatment occur amongst children.

During lessons, divide your class into small groups. Place the child with autism in a group where children are helpful and supportive. Form "buddy" pairs for indoor classroom activities, where in you may team up children with autism with a good, caring and helpful friend.

Always keep an eye on these children in class. You may request the child to sit at the first bench so that he/she is more attentive in class. Intermittently call out their names to ensure their attention. Use visual aids to facilitate learning. Incorporate all the strategies for teaching the child, as explained in section of psychological intervention. Also, incorporate behavioral strategies (psychological intervention) that work best for the child.

Every parent wants to know from their child "What happened at school today?" Often the response to this is not satisfying enough and that may bother you. A small note book that shuttles between home and school with the child can bridge the gap. Put this book into his/ her back pack. It can contain Xerox copies of two half page forms for each day at school. The parent must fill out the Notes from Home page each morning and the teacher completes the Notes from School page just before the day at school ends. A sample is presented here (Source: 1001 Great

Ideas for Teaching & Raising Children with Autism or Asperger's :

Schools must set up a barrier-free environment for integrating children with autism and augmenting their abilities. The school environment can be stressful due to its complexity and the constant unpredictable changes. The child is faced by one or more of these challenges in school:

- Concentrating and attending to a task
- Following instructions or commands
- Participation in the classroom
- Behavior difficulties
- Coping with transitions
- Coping with sensory bombardment (overload of many sensory stimuli at a time)

Provide a structured environment specifically for the child with autism, keeping in mind his strengths and needs. It must be conventional, safe and organized. For a structured environment, you need to make adaptations in your class arrangements, routines, and expectations to accommodate the abilities, needs and limitations of the children with autism. The figure below classifies the environment into three- physical, social/emotional and learning.

Modifications explained in the section of modifications can be incorporated in the school environment too. These will reduce the challenges faced by children with autism in the school environment.

Keep a record of emergency contact numbers (example, mother's or father's mobile number, etc.)

Dispersal from school can be a stressful situation due to the chaos. Allow children with autism to exit the school premises before relieving the others.

Teacher has the potential to take children with autism at a higher level, make them productive for the society and help them attain maximum independence. With the help of knowledge of autism, getting well equipped with right strategies to tackle the problems faced by these children and right attitude, the teachers can direct the future of children with autism towards the right direction.

NOTES FROM HOME

Date: _____

LAST NIGHT I:

slept well didn't sleep well Why? _____

TODAY I AM FEELING:

happy sad sleepy frustrated just OK well rested

Note from parent (special instructions, interesting experience):

Ask Julia about (something that happened after school that she wants to share):

Please call today. Phone number and best time to call: _____

NOTES FROM SCHOOL	Date: _____
TODAY AT SCHOOL I WAS:	
<input type="checkbox"/> happy <input type="checkbox"/> sad <input type="checkbox"/> sleepy <input type="checkbox"/> frustrated <input type="checkbox"/> just OK	
ACTIVITIES TODAY:	
<input type="checkbox"/> library <input type="checkbox"/> PE <input type="checkbox"/> music <input type="checkbox"/> assembly <input type="checkbox"/> other : _____	
Art: _____	
Science / Social studies: _____	
Math: _____	
Books / reading: _____	
This week we are studying/working on: _____	
Special Notes / Questions: _____ _____	

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33. Vocational Guidance

Myth... "If a child has autism, he/she cannot do anything...Unproductive for the society..."

Fact... "A child diagnosed with autism can be productive, independent and live a good life with the right vocational training and guidance..."

Children with Autism Spectrum Disorder transition into their teenage and adulthood and eventually new challenges surface for the individual and the entire family. Most parents are extremely concerned about the future of their children with autism. Doubts like "Will my son develop the necessary life skills to lead an independent and satisfying life?" may haunt you as your child grows. As parents you would naturally want your child to succeed in life, have a job and earn to have a self-sufficient life.

When should you start planning about your child's vocation?

When it comes to planning future careers for children with autism spectrum disorders, it must be understood that they require specific skill training and support for future employment. Children with autism often require much more practice within a supportive environment before they can flawlessly demonstrate employment skills in real situations. Starting early will help to ensure they are on the road to getting and keeping a job in a career of their choice. Following basic education up to a level that the child can sustain and is entitled to, pre-vocational and vocational training may be sought. Children with autism spectrum disorders have great potential in the area of employment. That potential is much easier to access when you start with the basics (teaching those skills that support employment) at an early age.

What is Vocational training?

Vocational participation is an important life-skill. Persons with autism often require specific guidance and training for trades or jobs that are suitable to them and fit their abilities.

Such training prepares them for job applications, interviews, provides training for a particular job (e.g. Telephone operator) and teaches them about professional skills and social conduct required at the job site. Vocational skills training for teens and adults

with autism, involves 3 stages towards becoming independent in their lives. They are as follows:

Stage 1: Vocational skills training for young adults with autism focuses on preparing them for employment through the development of essential work-related skills, like:

Creating a resume

Developing job searching and interviewing skills

Fulfilling job requirements

Interacting appropriately with co-workers and management

Managing job stress

Presenting themselves professionally

Stage 2: Trains for Living skills. These include skills which are necessary to function properly on a daily basis, such as self-care, cooking and cleaning, budgeting and bill paying, managing a bank account, grocery shopping, and good health habits.

Stage 3: Includes social integration skills. These skills include interacting appropriately with others, participating in recreational and leisure activities, using public transportation and other public services, engaging in friendships and maintaining relationships.

Vocational training programs begin with a detailed assessment of the person with autism. An important part of vocational skills training is assessing skill levels to determine what job or career path may be most appropriate. A skills assessment typically addresses 3 primary areas:

- Strengths: What are the areas of greatest abilities?
- Interests: What is most meaningful or important to him or her?
- Needs: What are the areas where he or she requires support?

Steps that help prepare for employment :

1. Enlist and identify job prospects for teenagers (for example, walking dogs, working in libraries, marketplace, making PowerPoint presentations, maintaining computers, etc.)
2. Identify mentors to guide and train
3. Visit different work places; take trips to different work setups (for example, assembly line, market place, library etc.)
4. Take up free online courses, attend community colleges, technical training schools etc.
5. Collect and go through trade journals and magazines
6. Identify positive skills and highlight them. Identify their savant skills and promote

them as their vocational option.

7. Create a portfolio or resume of oneself
8. Focus on selling skills not oneself
9. Practice presentation and interview skills
10. Practice and train for social skills necessary for the job

The outcomes of a vocational skills assessment will help in developing an individualized vocational profile and treatment plan. A personalized training program may lead to increased confidence and motivation. It helps in identifying and providing the best reinforcements for appropriate work-related behaviors.

What are some of the types of Vocational Training available?

There are two schools of thought with respect to training people with autism for job-specific tasks: train and then place (i.e. pre-employment training), and place and then train (i.e. 'On the job' training). This means that the individual may first undergo complete skill training in a conducive set-up, where he has the opportunity to practice and learn. On the other hand training may be provided as an ongoing process at the job-site after placement. They may also be placed at centers for a paid or unpaid internship. This is one of the best ways for any individual to learn more about a specific job or career option. It is especially effective for adults with autism to receive one-tone focused training, which may be offered in this type of setting. The decision about the type of vocational training, to which your child should be enrolled, depends on the assessment done by a trained Occupational therapist.

What are the behavioral strategies you could use for career planning?

Incorporating the following strategies can prepare and direct your child towards career planning in a co-operative and matured way.

- Make functional job related skills part of their daily routine. For example, setting an alarm clock to ensure he or she gets up in time every morning, would be a beneficial in the future. Other skills might include being on a schedule, practicing good hygiene, or ordering a lunch. These should be well achieved by the time your child gets his first job.
- Set limits for children with autism. For example, watching television or obsessing over non-functional routines or interests. This would prepare them to keep up with the limits which are usually set at a place of employment.
- You must create daily time-tables that require your child to follow a schedule. Permit participation in their preferred interests or fun activities (the ones that they could do all day if allowed) only after the required chores are done correctly.
- Have zero tolerance for poor behaviors. Do not allow your child to display social behaviors that are unacceptable. Do not make the mistake of forgoing behaviors

by attributing them to the autism. Do not let autism be an excuse for poor behaviors that will get in the way of being a functional adult.

What strategies can you use to teach social skills necessary for future employment?

- Teach functional social skills with role-play and prompted practice. Settings like scouts/ guides or sports, where children are involved in structured activities and have a secondary opportunity to socialize, will be useful.
- Direct eye contact can be very uncomfortable for those with autism. Adults with autism who are high functioning often state that they lose comprehension when they have to make eye contact. Explain about situations when eye contact becomes mandatory (like a job interview) and have them practice eye contact during role playing.
- Teach children with autism to read facial expressions and feelings. Children with ASD have a hard time recognizing and understanding the more subtle aspects of social communication, like facial expression. Vague expressions like disappointment, questioning or gratitude are completely missed. They have to be taught and practiced specifically. Strategies explained in the previous chapters on Speech therapy and Psychological therapy can be referred to.
- If more complex language and conversation skills are absent or severely delayed, a visual communication system may be a necessity. Public schools can provide speech and language services to assist with this objective.

What steps can be taken towards successful employment?

- Investigate the available career options. Making career choices can be a complex task for those on the autism spectrum. They may be proficient visual thinkers or may be more inclined towards numbers and math. Look at careers that center on their strengths or interests. Try to define career and job choices that have set daily routines, fewer social and emotional demands and no adverse sensory inputs.
- Contact service agencies. Some agencies have lengthy application processes and a large time lapse between applying and actually getting the services. Parents should contact agencies when their children are young and ask what the waiting time is to receive services. Get the child on their wait-lists. The American Autism Society recommends contacting state departments of vocational rehabilitation, state employment offices, mental health agencies and disability organizations for vocational rehabilitation.

Are there sufficient job opportunities for Individuals with Autism?

Until a decade ago, the job opportunities for people with autism were slim. Opportunities for individuals with autism are minimum due to decreased awareness and stereotypes about the disorder. Today, with increased autism awareness and support services for

people with autism and their families, opportunities are growing. More and more employees today are aware about persons with autism and their valuable talents or abilities that can benefit their organizations. Employment opportunities are not limited to people with mild autism, as jobs are also available for people with moderate to severe case of autism who are able to seek employment and function in a job.

What are the possible challenges that Individuals with Autism may face?

Finding a job and succeeding in one is a challenge for anyone. For a person with autism, the transition into a job environment presents more challenges due to communication and social difficulties. Common workplace challenges faced by people with autism include:

- Problems in fitting into the general workplace environment, especially if the people are not familiar with the needs and problems of persons with autism.
- Misunderstandings due to difficulty in understanding others emotions and providing appropriate responses.
- Difficulties in understanding verbal instructions.
- Repetitive and obsessive behaviors may cause conflicts at the work environment.
- Some coworkers and employers may not be helpful.
- Both autism employees and their employers can overcome all of these challenges through training.

Employers who want to truly provide equal job opportunities and a healthy work environment can learn more about autism and can contact vocational centers or support services for guidance. Adults with autism seeking employment can also enroll into programs through non-profit organizations.

What are the possible careers options?

Many of the traits that can make fitting into society a challenge, have provided the foundation for successful careers to people with autism traits common to the autism mind. These traits are their:

- Need for structure (set, simple and specific ways),
- Intense focus on activities of interests,
- Compulsivity (being over particular about things),
- Repetitive behaviors
- Disinterest towards office politics, controversies, gossip, tiffs between workers, etc. and
- Understanding of some complex systems that may be difficult for many of us.

All of these can be directed towards positive use in the work force.

Finding successful employment in a preferred career of specialized interest may be difficult. While the individuals may possess skills in several aspects, those related to their individual interests tend to be very strong and often well above average. Based on the skills identified, suitable jobs may be sought.

Some practical examples are explained below:

- Individuals, who have a flair for arts can get into creative jobs like becoming a painter, fashion designing, pottery, musician, etc.
- Individuals with autism who give precise attention to details are apt to take up jobs like jewellery designing, watch repairing, embroidery, etc.
- Individuals who are good at following simple commands and require structure can take up jobs which require less decision making like sitting at a telephone booth, toll booth, working at a canteen, operating a Xerox machine, etc.
- Individuals who are capable of understanding complex systems, skillful in mathematics and who have an innate flair for technology could take up an occupation related to the field of engineering for example; mechanical engineering or computer programming, systems designs, graphic designs, hardware servicing, etc.
- Individuals with autism having good language abilities could be journalists in print media as they would be able to state honestly and confirm facts. Gathering facts in an organized manner and reporting them can be second nature to many with autism.
- The need for repetition is common in autism. Such individuals could take up jobs at an assembly line, in a packaging industry, the cafeteria, printing press which are repetitive in nature and are suitable.
- Individuals with autism for whom social interaction and communication is a major issue, working with animals maybe a comfortable and enjoyable field of employment. They may be excellent at interacting with animals making them good veterinaries or veterinary assistants. Others may find their place in the farming industry, animal husbandry or dairy industries.
- Individuals with autism are usually very sincere, trustworthy and who are good with directions could be handed over the work of delivering letters, paying bills, etc.
- For individuals with moderate to severe degree of autism supervised job settings are appropriate. They may be able to function in groups, in a protected environment, under the guidance of a trained supervisor. For example; rug weaving, block printing, making greeting cards, paper bags, envelops, wood carving, etc.

The professionals at vocational training facilities and placement centers need to be aware of all aspects of the life of adults with autism. Frequently, changes in life situations

will cause stresses that can increase unusual problematic behaviors at the work site. The job trainers need to be aware of these changes and provide a setting that helps the individual cope better. By using a holistic approach towards the individual, the chances of successful vocational placement increase.

Jobs for Visual Thinkers

Industrial design	Computer network
Graphic arts	Drafting
Auto mechanic	Computer repair
Handcrafts	Convention AV technician
Photographer	Animal trainer
Architect	Veterinary technician

Jobs for Music and Math Thinkers

Math teacher	Scientific researcher
Electronics Technician	Music teacher
Chemist	Computer programmer
Engineer	Physicist
Musician/composer	Statistician

Jobs for People with Poor Verbal Skills or Non-Verbal

Shelve Library Books	Factory Assembly Work
Running Copies and Mail Room	Lawn and Garden Work
Recycling Plant / Warehouse	Stocking Shelves
Inventory Control	Handcrafts

Jobs for Verbal Thinkers

Stocks and bonds analyst	Journalist
Translator	Librarian
Copy editor	Accountant
Specialty Retail	Bookkeeper & record keeper
Budget analyst	Special education teacher
Book indexer	Speech therapist
Inventory control specialist	Legal researcher
Stage actor	

Satoshi Tajiri, the creator of Pokémon He is referred to as a child as 'Dr. Bug' by friends because of his autistic fixation with bugs. Satoshi Tajiri later created one of the most popular video game franchises in the world, second only to Super Mario Brothers. He was diagnosed with Asperger's syndrome; Satoshi Tajiri has been described by Nintendo officials as exceedingly creative but reclusive and eccentric.

Stephen Wiltshire: An artist Stephen Wiltshire as a child was mute and did not relate to other people. When he was 3 years old he was diagnosed to have autism. He had no language and lived entirely in his own world. He is an artist who draws and paints detailed cityscapes. He has a talent of particularly drawing lifelike, accurate representations of cities, sometimes after having only observed it briefly.

Temple Grandin, American doctor of animal sciences and bestselling author: Temple Grandin is an American doctor of animal science and professor at Colorado State University, bestselling author, autism activist, and consultant to the livestock industry on animal behavior. She also created the "hug box", a device to calm autistic children. She was diagnosed with autism at the age of 2. At times, while she walked down the street, people would taunt her by saying "tape recorder," because she would repeat things over and over again. Grandin states that "I could laugh about it now but back then it really hurt."

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34. Assistive Technology

Assistive Technology also known as adaptive technology is an umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities (including autism). Assistive Technology refers to "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities". Individuals with autism are limited in their functions due to several problems such as poor communication, lack of verbal speech, sensory issues, etc. In order to decrease their dependence on you for activities and maximize their functioning in society, some of the devices given in this chapter may be utilized, as directed by an occupational therapist or at times a speech therapist.

According to Susan Stokes, an autism consultant, children with autism generally respond better to visual stimuli than to auditory devices so most assistive technology devices help them process them information visually, or in conjunction with an auditory device. Eye contact, social interaction, self organization and academic skills are a few of the areas where the right assistive technology can make a big difference in the life of child with an autism spectrum disorder.

What assistive technology can you use to augment communication?

Children with ASD appear to learn differently and frequently have difficulty with spoken and written language expression. Children with ASD may not speak at all, they may speak just a few words, or their speech may be irrelevant and meaningless in a given situation. They may have difficulty understanding spoken language - even if their hearing is "fine". Sometimes they may also not be able to understand gestures, body language, and tone of voice that convey subtle differences in meaning. Children with ASD often demonstrate difficulty with overall motor planning. The motor planning involved in speaking - coordinating the mouth, lips, tongue and facial muscles - is extremely complex and requires sophisticated motor planning ability. There are some adaptive devices which teach them how to express their wants and desires, which not only improve their social skills, but make them, feel more independent and confident as well.

Visual Representation Systems

Picture Exchange Communication System (PECS) is the best form of visual communication technique for autistic children with almost no language skills. The Picture Exchange Communication System (PECS) is a type of augmentative and alternative communication (AAC) device. As explained in the section of speech therapy, the system uses picture cards for communication. It is one method that a child with a severe speech disorder can use to indicate his basic needs and wants, thus reducing the child's frustration and social isolation and thereby, encouraging communication. Either you can buy cards from market or make it at home. If you are making at home, draw an image on a piece of paper or cut an image out of a magazine and stick it to the paper and label it. You can separate the cards into categories so that your child can easily access them like food items in one row and toys in different row etc. Follow the protocol given in section of speech therapy, for training.

Speech Generating Devices

Speech Generating Devices (SGDs) refer to the several types of voice output devices, designed to help those who struggle with speech. SGDs range from simple, short voice messages to computers, complete with several complex messages. SGDs help caregivers and children, because they do not need to learn a picture system; they just need to listen to the spoken message. Some SGDs come with a visual display that will show a symbol or picture of what they are discussing to make it easier for the child. More complex ones allow children to type their requests into a device, and it is spoken out loud for the caregiver.

According to Missouri Assistive Technology Advisory Council, a combined intervention of low technology techniques like sign language and PECS and SGDs will improve the child's communication skills. While the child may not communicate naturally, he/ she will develop skills to converse at a functional level. Some children may feel that SGDs are fun since it looks and functions like a normal laptop and makes them feel less stigmatized.

Voice Output Communication Aids

Voice Output Communication Aids (VOCAS) are visual representation systems through which learning and communication will be easier for these children. Most of these are simple to operate and relatively inexpensive, running on batteries or electricity and producing excellent sound quality. The classic device gives spoken directions. A set of picture cards that come with the machine can be run through by the child, prompting the device to repeat some or all of the directions.

Multi-purpose devices for children with autism

Many devices and systems can be incorporated into your child's daily activities to simplify demands and ease performance. Technology can also help improve attention,

sitting tolerance, fine motor skills, generalization skills (from computer to related non computer activities), decrease agitation, decrease self-stimulatory behaviors and decrease preservative responses like. The computer and iPad are highly useful in accomplishing all the above.

Computer Assisted Technology

Many children with autism are highly interested in and motivated by computers. Therefore, computers should be infused into the child's daily curriculum and not used solely for reward or recreational purposes. Computer assisted learning can focus on numerous academic areas as well as, provide an appropriate independent leisure time activity for people with autism. The computer does not send confusing social messages. The computer places the child in control, allowing the child to become an independent learner.

- Adaptive Hardware**

In order to access the computer, some children with autism might require that the standard computer be adapted with certain devices.

Touch Window: The purpose of the touch window is to allow the child to "navigate" and "interact" with the computer by touching the screen, rather than operating the mouse. Touch window/ screen can be easily mounted on the computer monitor with the user simply touching the screen to replace mouse actions.

The use of a touch screen can assist a student who experiences difficulty in understanding the abstract relationship between the mouse clicks or movements and the resulting actions on the screen. With a touch screen, the concrete relationship between what the child sees and what the child activates by his own movements is established.

Intelli-keys: This is a commonly used alternative keyboard that easily connects to a computer. It is an ideal solution for students who have difficulty using a standard keyboard. In order to operate the computer, the child simply pushes various locations on an overlay that is placed in the Intelli-keys. Standard overlays for the alphabet, numbers, mouse direction and a 'single switch hit' are included with the Intelli-keys. In addition to acting as an alternative keyboard, the Intelli-keys has 4 switch jacks located on the side of the keyboard, so that a single or multiple switches can be connected to the computer through the Intelli-keys for children to access via a single switch hit. This would allow children with limited fine motor control to access the computer.

Big Keys and Big Keys-Plus: This is an alternative alphabet keyboard that has been specifically designed for young children. The keys are large (1 inch squares), with the various alphabet letters color coded to help children more readily find specific keys (i.e., vowels in one color, consonants in a different color). The keyboard is also arranged in ABC order for easy access for these children.

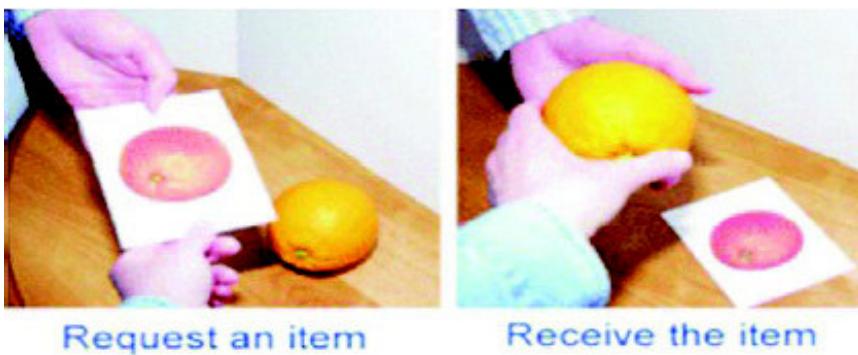


Figure 34.1 : Use of PECS



Figure 34.2 : Speech Generating device with visual display



Figure 34.3 : Use of Computers for academics



Figure 34.4 : Touch Window



Figure 34.5 : Intelli-Keys

Trackballs: Trackballs come in various sizes and shapes, and allow the child to move the mouse around the screen by rolling a stationary "ball" around with either his fingertips or hand. Some children with autism can master the mouse operations with a trackball, and eventually transfer to use of a standard mouse.

- **Software**

There are numerous software programs available that focus on a variety of skill areas such as language skill, attending skills, problem solving skills, fine motor skills, academic skills and leisure time activities. Use educational CDs that teach basic concepts using interesting visual and auditory representations.

The iPad

The iPad, like other computers, is an effective tool for many people on the autism spectrum. It is easy to carry and more advance than computers and laptops. The touch screen and layout make the iPad more accessible for children with coordination or learning difficulties; these children may find sliding and tapping easier than either typing or writing. The iPad moreover, is helpful for calming and focusing children who are always on the go.

The iPad can also be used as a communication board or augmentative communication device. Due to the customization options and because the iPad is a 'cool tech device' that doesn't immediately mark a child as different, many see it as a more attractive option than the more traditional devices.

The iPad can be used more effectively with the addition of several "Apps" that are specifically effective in improving communication, behaviors and social skills in children with autism.

The book titles "Apps for Autism" by Lois Jean Brady is an amazing collection of over 200 such applications.

Video taping

Videotaping is often highly successful among people with autism for teaching language and social skills. Children appreciate the predictable outcome, often watching the same video repetitively. Videos can be made of tasks, such as setting the table, getting ready for school or to increase vocabulary by naming objects or actions. Videos can be very useful in the social arena, with opportunities to demonstrate both acceptable and unacceptable behavior. For example, social interactions can be modeled, such as smiling and saying 'hello' to classmates. Tone of voice, body language, personal space, facial expressions and vocal volume can be observed and discussed.

Others

These can be used for communication, learning, remembering steps or activities, etc. A small hand held erase board can be used by a child who can quickly draw or write to

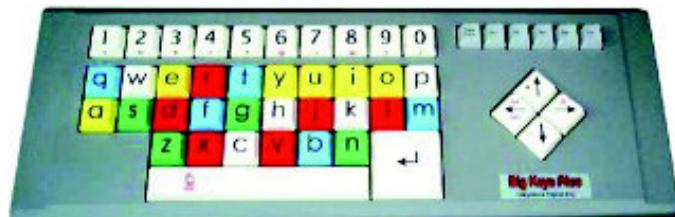


Figure 34.6 : Big Keys and Big Keys-Plus



Figure 34.7 : Track Ball



Figure 34.8 : I-Pad



Figure 34.9 : Beeping Ball

communicate his/ her needs. A simple dry erase board with a daily, weekly and/or monthly schedule can help with everything from remembering schedule to sequencing activities. Alternative ways to present schedule information can include a binder, clipboard, file folder, wall mounted chart, etc.

If written words are difficult, especially for children, try black and white line drawings, photographs or object symbols (such as a ball for playtime). These can be placed in sequential order to help the person with autism go through the steps needed to independently complete a task or go through a day. Individual tasks can be further broken down as needed, and "all done" envelope placed at the end of the sequence to indicate a task has been accomplished.

Some adaptive devices for enhancing the child's social interaction and participation in play and leisure activities are:

adapted toys and games	adapted puzzles
adapted sporting equipment	universal cuff to hold crayons, markers
modified stampers and scissors	beeping balls
arm support for drawing	graphic design software
computer games	

Adaptations to reading materials include:

change in text size, spacing, color, background color	multimedia presentation format
use of pictures with text	recorded material
adapted page turning	software for organization (i.e., Inspiration)
book stands	software for concept development
talking electronic device	highlighted text
scanner with talking word processor	electronic text books

Adaptations for ADLs and handwriting skills have been mentioned in ADLs under occupational therapy. Some assistive devices have also been covered in the section of modifications at home.

Safety

Safety is a major concern for parents of children who have seizures or self-injurious behaviors. Children with severe episodes of epilepsy may fall and hurt themselves. It is advisable to use proactive gears like helmets, elbow and knee pads, especially when outdoors. Also, helmets can protect a child who is prone to head-banging. Bitter tasting

tapes or bandages can be applied over the hands to prevent your child from self-biting. Spray Bitter Apple over objects that are commonly put into the mouth.

Typically, children with autism process visual information easier than auditory information. Any time we use assistive technology devices with these children, we're giving them information through their strongest processing area (visual). Therefore various types of technology from "low" tech to "high" tech should be incorporated into every aspect of daily living in order to improve the functional capabilities of children with autism. To decrease their dependence on you for daily activities and maximize their functioning in society, some of the devices given above may be utilized, as directed by an occupational therapist or at times a speech therapist. These devices may be able to provide them with an independent life.

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35. Apps for Autism

As technology evolves, many parents with autism children are finding some support with devices such as the ipod touch, iphone, ipad, tabs and android phones. Some apps have helped families improve communication whereas others have benefited the child directly. When looking for apps for children on the autism spectrum (ASD), it is important to look at all educational apps and not just those that are tagged as autism apps. This list was developed to provide apps based on common learning characteristics and traits that are typical for children with ASD. It is important to remember that all students learn differently and selecting apps should be based on the unique learning needs each child.

Applications for iPad, iPhone & iPod Touch:

Sr. No.	Name of the App	Price	Description
Educational Apps			
1.	ABA Flashcards	Free	Flash cards can be a great tool for fostering the mastery of new words, building vocabulary and conveying new concepts.
2.	I Hear Ewe - Animal Sounds for Toddlers	Free	Entertain and educate young children with this simple game full of 24 different authentic animal sounds and 12 different vehicle sounds.
3.	PreSchool Adventure	\$1.19	Contains eight simple activities that you can do with your young toddlers and preschoolers: Dot?to?Dot, Numbers, Artist Coloring Book, Typing the ABC Animals, Ocean Colors, Space Shapes, Monkey Body, Farm Sounds & Animal Matching.
4.	Tell Time	\$2.49	Designed to help people learn to tell the time. Analogue and digital clocks are used.

Sr. No.	Name of the App	Price	Description
5.	FirstWords Deluxe	\$5.99	Helps your child with learning their letters and learning to spell words.
6.	FirstWords At Home	\$2.49	Helps your child with learning their letters and learning to spell words.
7.	iWrite Words	\$3.99	iWriteWords teaches your child handwriting while playing a game.
8.	Picture Association	\$4.00	This app is a simple drag-n-drop game and is full of beautiful photographs of many common objects found in everyday living.
9.	Words in Pictures	\$0.00	The first app expressly made to give parents, teachers and therapists an effective, customizable, portable tool for visual communication to the child or adult suffering from Autistic Spectrum Disorders or intellectually impaired.
10.	Mee Genius! Kid's Books	Free	A digital text eReader of children's books in the public domain. Comes with 8 books, need to download free or purchase others - about \$1.99. All books are narrated by a human voice. Highlights the words as it reads.
11.	Flashcards	\$3.99	A flashcard app to study anything. Divide cards in categories with 3 response levels and tag them for more studying. Download over 2 million "decks" created by users.
12.	LetterSchool	\$3.99	An amazing, intuitive game to learn all about letters and numbers: writing, counting, phonics and more.
13.	Intro to Math	\$4.99	This app teaches the basic foundations of math, including number symbols, sequence, order and spatial relationships. Learn to read, write and understand numbers from zero to nine, through a series of interactive, guided and challenging activities.
14.	Match & Find	\$8.99	This is an app designed to help develop young children's memory, matching, searching and sequencing skills. Working memory is very

Sr. No.	Name of the App	Price	Description
			important for the development of language and numeracy, and the carefully designed activities in this app can help children train and improve their auditory and visual working memory.
15.	DotToDot numbers & letters	\$1.99	Dot to dot puzzles practice number counting, learning the multiplication tables and repeating the alphabet. Free lite version available.
Social Communication Apps			
1.	Autism Xpress	Free	It is designed to encourage people with autism to recognize and express their emotions.
2.	Locabulary Lite	Free	Use the iPhone, iPad, iPod Touch to communicate words, phrases, and sentences.
3.	Model Me Going Places	Free	A visual teaching tool to help your child learn to navigate challenging locations in the community. Each location contains a photo slide show of children modeling appropriate behavior.
4.	StoryKit	Free	Gives users the ability to create story books on their iPad, iPhone, iPod Touch
5.	Tap To Talk	Free	Provides children with the ability to communicate their wants and needs via pictures and words on their device.
6.	Expressionist	\$12.99	Expressionist is designed to help users to express, and to help users to model expressions
7.	AutoVerbal Guy Talk	\$5.99	An app designed to use iPad voice output for those who have trouble using verbal speech.
8.	Stories2Learn	\$16.99	Stories2Learn (S2L) offers parents and educators the ability to create personalized stories using photos, text, and audio messages. These stories can be used to promote an individual's literacy, leisure, as well as social skills. In addition, S2L comes preloaded with

Sr. No.	Name of the App	Price	Description
			a story illustrating the skills necessary to play a game with a friend.
9.	Proloquo2go	\$239.99	It aims to provide augmentative and alternative communication for people who are non-verbal or who are using very little verbal speech. The application can be tailored to meet the specific needs of these people and can be very successful in aiding communication.

Speech & Language Development Apps

1.	Words in Pictures	\$0.00	The first app expressly made to give parents, teachers and therapists an effective, customizable, portable tool for visual communication to the child or adult suffering from Autistic Spectrum Disorders or intellectually impaired.
2.	Speak It!	\$2.49	An application to turn text to speech. Large amounts of text can be inputted then 'spoken' by this app.
3.	Touch Talking	\$2.99	Designed for young toddlers as a speech learning assistant, displaying pictures of common objects. When the child taps the picture, the name of the object plays.
4.	TapSpeak Button	\$12.99	TapSpeak Button modernizes the idea of a mechanical switch that records and plays messages. The idea has been taken and extended it to provide a portable, convenient, and stigma-free tool to use for basic teaching and communication tasks.
5.	iConverse	\$12.99	iConverse is an educational tool designed for young children, autistic individuals, and individuals with other communicative disabilities, and also toddler-aged children who have yet to master language.
6.	ArtikPix	\$59.99	ArtikPix ? Full is an articulation app with flashcard and matching activities for children with speech sound delays.

Sr. No.	Name of the App	Price	Description
7.	See Me Talk	\$59.99	This is an easy to use augmentative and alternative communication (ACC) app for those who have difficulty communicating effectively. It is based on a picture exchange system developed for people with speech delays to communicate their needs independently and effectively.
8.	Avatalker ® AAC	\$189.0	A full-featured augmentative and alternative communication solution designed for the iOS platform (Apple's iPad and iPad Mini). It gives nonverbal children and adolescents the ability to build phrases and sentences pictographically, which is then converted to audible speech.

Behavioural Intervention Apps

1.	ABA Find It!	\$0.99	How do you make learning more engaging for children with autism or other special needs? Make a game of it! ABA Find It! provides children with autism and other special needs with a fun and interactive approach to learning.
2.	Behavior World	\$ 0.00	Behavior World is a customizable, positive reinforcement tool for parents, teachers and other individuals working with children. Users have the ability to create and personalize game-like behavior management token economy charts that can be used to help children improve their behavior and learn new skills at school AND home!
3.	Caught Being Good	\$0.99	This app makes your life easier and more enjoyable by effectively using positive reinforcement instead of punishment to shape your children's behavior. Using Caught Being Good will increase your child's self esteem, bring focus to the positive, promote desirable behavior and reward good behavior instead of bad.

Sr. No.	Name of the App	Price	Description
4.	IF... The Emotional IQ Game	\$0.00	Help children develop "EQ" (Emotional Intelligence) with a wide variety of skills and tools, all learned through engaging, motivating and self-paced game play in an epic educational adventure game that kids love.
5.	Plan with Me	\$2.99	A behavior support planning tool that will focus on the person and their support needs. A user friendly interface to enable all to be involved in behavior planning. Visual representation of behaviour escalation helps with understanding of the behaviour and planning which strategies to use when.
Sensory Differences Apps			
1.	Brain Works	\$11.99	This app assists with implementation of a sensory diet by providing over 130 sensory activities. Activities are selected based on how the individual is feeling at the time and are different based on the identified environment.
2.	White	. \$1.99	Noise Provides ambient sounds and pictures to help you focus, work, relax or sleep. 40 different sounds and pictures. Mix your own combination of sounds
3.	Little Lilly's Touch Book	\$2.99	Lilly is a little girl who loves to go barefoot but hates the feeling of just about everything she touches. Written for kids with sensory issues. Pictures move by touch and animate with tilt of iPad. Audio narration.
Applications for Android Users:			
1.	Color Car	\$0.99	This app is created to introduce autistic children to colors using cars. In this app we use cars to teach children colors. The style user "discrete trial trainingA" for the purpose of encouraging the learning of colors.
2.	LetMeTalk	\$0.00	LetMeTalk is an AAC app which lets you form sentences with images and speaks the sentence. It comes with 9000 easy to understand images by the Arasaac project,

Sr. No.	Name of the App	Price	Description
			supports 16 different language (including english and spanish), lets you add your own images and has voice support.
3.	Letter School	\$1.19	An amazing, intuitive game to learn all about letters and numbers: writing, counting, phonics and more.
4.	Pogg	\$0.99	Pogg is a fun educational game for young children, as well as a proven useful tool in kids' language development and speech therapy.
5.	Smart Steps Mobile	\$0.00	Smart Steps Mobile is for easy decision making in everyday life situations such as a lost backpack or a late ride. The app walks the user step-by-step through the decision making process. Safety tips and social skills are built right in, and the app user is prompted to call for help.
6.	The Brainymajig ABC	\$3.32	The Brainymajig ABC is an educational app that aims to teach young children the alphabet with science in mind. The app offers an exciting and dynamic way for children to learn, using vivid colours and friendly characters. The app uses the English Phonics code to ensure your children are learning the same sounds that they would be taught in school.
7.	ZacZoo	\$0.99	ZacZoo is a discrete trial training (DTT) based application. DTT is a learning technique used by autism behavioral instructors to provide basic understanding of key early concepts. DTT is a card matching drill.
Social Communication Apps			
1.	AAC Autism Talk	\$2.43	AAC Autism Talk Now android app help kids with autism learn and communicate at a different pace. The app focuses on analyzing pictures, understanding the way to speech and playing around with emotions. It is a communication (AAC) app that teaches

Sr. No.	Name of the App	Price	Description
			children how to convey their needs in everyday life through sentences, symbols and pictures.
2.	Easy Questions	\$ 0.00	Practice conversation and "Wh" questions with recording and playback options. Contains 90 questions - a mix of conversation and "wh-" questions. The app will speak the question and has the ability to record and playback a response as well so that people of any age can practice asking or answering questions.
3.	Samsung Look At Me	\$ 0.00	This program was developed by Samsung, in collaboration with professors, doctors and UX designers. Seven scientifically-produced missions were created to help children with autism make eye contact, read facial expressions and express their emotions. 20 children trained on the program over eight weeks and *60% of them showed improvement in making eye contact.
4.	Training Faces	\$2.99	Game for individuals with Autism and other special needs to recognize emotions to help improve social skills by recognizing the emotion, the cause behind the emotion and speedup recognition.
Speech & Language Development Apps			
1.	AAC Speech Communicator	\$0.00	AAC that uses pictograms to create grammatically correct sentences. Text-to-speech. 5,000 pictures
2.	Aut2speak	\$1.00	Aut2speak is a communication keyboard for those with non-verbal / pre-verbal autism who already know how to type.
3.	Autism my Voice Communicator	\$2.99	Autism myVoice Communicator is an app designed to aide non-verbal children (even toddlers) and adults with communication. As seen on CBS 60 minutes, (Apps for Autism) autism apps like Autism myVoice is also considered to be an easy to use augmentative

Sr. No.	Name of the App	Price	Description
			and alternative communication (AAC) device.
4.	Pecs Pics+ (Autism)	\$1.99	Pecs Pics+ (Autism) is a picture application that allows you to set a picture of your choosing to a square. (Generally items that your child is familiar with and would like to be able to request) Then you can record your own word for that item in the picture in any language you would like. Once your voice is recorded the child can simply tap the picture to play your recording. Therefore being able to make a request with your own words.
Behavioural Intervention Apps			
1.	ClassDojo	\$0.00	ClassDojo is a free behavior management app that allows for individualization of specific behaviors, immediate student feedback, and online and printable reports for parents and teachers.
2.	ABA Datasheets: PIR	\$0.00	This app will make Partial-Interval Recording data collection convenient, easier and automatic.
3.	AAC Autism Talk Now	\$2.43	This app help kids with autism, learn and communicate at a different pace. The app focuses on analyzing pictures, understanding the way to speech and playing around with emotions. It is a communication (AAC) app that teaches children how to convey their needs in everyday life through sentences, symbols and pictures.
4.	This for That : Visual Schedules	\$ 4.99	Help your child perform daily routines independently with This for That: Visual Schedules! Easily create your own custom visual schedules that break tasks down into simple steps and use visual cues to help the child succeed! Include a picture of the reward the child is working toward to motivate him or her to complete the task! This for That was designed for children with autism spectrum

Sr. No.	Name of the App	Price	Description
			disorder and is a useful tool for any child who needs help completing tasks independently at home, school, or in the community.

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6. <http://momswithapps.com>

36. Modifications At Home

Most parents and caregivers would view safety as a significant concern for their children in the home environment. Modifications such as installing gates in stairwells and doorways, covering electrical outlets, and using locks on drawers are some of the things many parents do to ensure safety. For parents of "typical" children, such safety precautions are usually necessary during the first few years of childhood, after which the child develops, matures and no longer requires the use of modifications. However, for parents of children with autism spectrum, making the house child-friendly may be necessary for a longer period of time. They need to account for several additional precautionary measures while planning for modifications / alterations in the house for safety of the child.

You need to first list down the various autistic behaviors of your child which could prove to be unsafe, for instance, breaking cups and plates, sweeping items off surfaces, dumping drawers, and climbing out, or breaking windows. Consider the consequences of natural curiosity and the reactions of such curiosity like putting items into appliances, flushing things down the sink or toilet, touching burners, turning on hot faucets, inserting items into electrical sockets, chewing on wires, and crawling in a washer or dryer. Finally, consider the potential dangers that can result from playing with matches, lighters or fire.

Often children with autism who display such behavioral concerns do not understand the ramifications of their actions, which at best can be bothersome and at worst can be devastatingly tragic. Therefore, it becomes compulsory for the caregivers at home to provide a safe environment and teach the children how to ensure safety.

There are several modifications that can be implemented at home and simple measures that can help prevent unsafe or inappropriate behaviors. An occupational therapist can help you in implementing the various strategies mentioned at your home. Establish priority areas for modification. Modify the most important areas first - such as your child's bedroom, bathroom, leisure areas, kitchen, etc. These are the primary areas of interaction for many children. When getting started, think about the room(s) in which the child spends maximum time. For some children, it would be a recreation/drawing room, whereas for others it might be the bedroom or kitchen. In addition, consider the

behaviors to be modified and the relationship of those behaviors to the environment. Behavior modification works to alter an individual's behavior through positive and negative reinforcement. Remember that behaviors always serve some purpose, and in order to alter a particular behavior it must first be understood. If the individual likes to put things in the toilet or run hot water in the bath, modifications should begin in the bathroom. If the child runs out of the house, modifications should begin with securing exterior doors with locks.

What are the various modifications you can do?

1. Use of Locks and Alarms Where Appropriate :

For individuals who run away or leave the home without supervision, it is important to place locks and alarms on main doors and windows that provide entry or departure from the home. It may also be necessary to use safety locks to secure items that may be unsafe for the individual. Many parents place these locks on bathroom and kitchen cabinets to prevent access to items in the cabinets.

2. Stuffing toilets/sinks :

Many children with autism are fascinated by playing with water. Some are fascinated with flushing things down the toilet or clogging the sink. Such behaviors can cause water to overflow and create a lot of hassles and cause damage. There are alarms that are attached to the intake pipes of a toilet or sink. When the alarm senses a leak or overflow, it will automatically shut the water off. Parents can make use of these appliances to make their home safer for their children.

3. Light Issues :

Many children are sensitive towards bright lights, and may need some modifications at home. The first consideration is the type of lights used at home. Children with autism tend to be bothered by fluorescent lights as they are too bright. If your child finds these lights disturbing, replace them with incandescent lights. It is also beneficial to have dimming switches for the lights so that you can control the brightness of the room. These can be easily installed to replace any regular switch for incandescent lights. This is useful when you want to help your child calm down or increase his/ her arousal levels. These are also helpful for children who have difficulties with sleep patterns.

Another consideration for lighting is the paint. For children with sensitivity to light, consider the colors and the tones that are used in the rooms. Avoid yellows, reds, and bright whites. Try to use softer tones of colors. Also, avoid glossy paint that reflects a lot of light.

4. Organize your House :

Children are particular about their things and routines, so the house should be neat, clean and organized. The organization, order, and structure in their



Figure 36.1 : Water Alarm



Figure 36.2 : Incandescent Lights



Figure 36.3 : Plastic Knobs for Stove

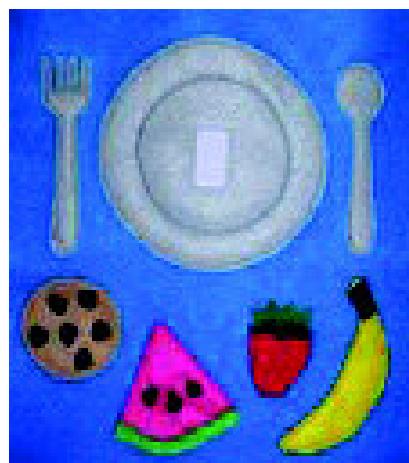


Figure 36.4 : Velcro to Attach to eating Utensils

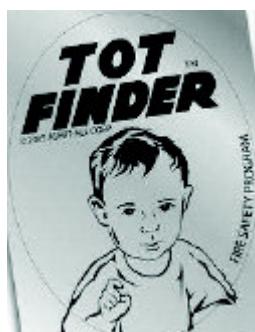


Figure 36.5 : Fire Safety Sticker



Figure 36.5 : Modified Study Room

environment are likely to help reduce the frustration levels, and thus the undesirable behaviors. Keep things placed in the right spaces, avoid clutter and do not change the settings too often.

5. Label everyday items :

Place visual labels (symbols, photos, words, textures) on functional items, rooms, drawers, and anything that has relevance for the child. By labeling the environment, a child on the autism spectrum may understand better, what is expected of him/her, and is less likely to engage in undesirable behaviors. In addition, if the child understands the function of an item (e.g., a piece of furniture), he/she are more likely to use it for its intended purpose. For example, by placing visual labels on the bed for sleeping, the child may be less likely to view the bed as a trampoline. Placing labels on drawers and closets will make it clear to your child where to put things away.

6. Make Electrical Outlets and Appliances Safe :

Cover or remove electrical outlets and access to electrical appliances. Use plastic knob covers (available at hardware stores) for doors, faucets, ovens, and stove burners. Lock the door to the room or rooms with the washer or dryer, appliances or power tools to limit access. Ensure that all wiring for appliances and electronics is concealed in a way that the child cannot play with the wires. Individuals on the autism spectrum are often too curious about how things work, but that can be coupled with a pervasive "unawareness" of dangerous situations - a potentially powerful combination when it comes to electrical materials. Also, loose electrical cords and proper earthing for the wires and electrical sockets will help ensure safety for your child.

7. Lock Dangerous Items Away :

Secure items that are dangerous if ingested such as detergents, chemicals, cleaning supplies, pesticides, medications and small items that a child may swallow or chew. It is easy for an individual with autism to confuse a bottle of yellow cleaning fluid with juice based upon appearance or to pour/spill liquids out of a bottle (some of which may be poisonous or toxic). Also, pills that look like candy can easily be eaten by mistake. Place such items out of reach or in drawers with locks.

Secure items/materials that are dangerous or unsafe if used without supervision, such as sharp objects/utensils (scissors, knives, razor blades). When unsupervised, many children like to cut things (clothing, curtains, wires, books, etc.) into pieces with scissors or knives. If necessary, use scissors that have blunted ends (child-safety scissors), and be sure to provide supervision when the child is involved in cutting activities.

8. Arrange the furniture appropriately :

Arrange the furniture in a way that "makes sense" for the activities the individual

is expected to do. That is, if the individual will be doing activities in sitting, ensure that there are clear table surfaces and appropriate chairs. If the child frequently runs out of a room via a predictable path, arrange the furniture and close doors so that he or she is unable to escape. Limit the need for excessive movement and/or transition. Move furniture away from shelves or places where the child may climb. Keep furniture surfaces clear (if the individual is a "sweeper") and place items out of reach on shelves or bins, or lock things away. In addition, use gates or barriers to provide safety from falling down steps or to limit access to certain areas in the home

9. Safeguard your windows

If your child likes to climb out of windows, place locks on them. Such special locks are available at the hardware stores. If your child breaks glass, replace glass windows with acrylic sheets.

10. Appropriate seating

Ensuring that the individual is seated properly at a table or work station can help prevent behavioral problems, such as throwing objects, knocking over furniture, self stimulatory behaviors, and acts of aggression. For example, some children need to be seated in chairs with arms or a wrap-around style desk when doing work. Others may need to be seated in a place where they cannot easily escape, such as against the wall or in a corner. In addition, a proper sitting posture (body at a right angle and feet flat on the floor) will help facilitate good learning and/or eating behaviors.

11. Use Visual Signs

Use dividers, tape boundaries, and signs as needed for setting expectations and limits. For example, the use of 'STOP' signs on doors, drawers, furniture, and appliances has helped some children understand that these items/ areas are off limits. For children who climb on high surfaces or enter areas that they should not, 'STOP' signs will let them know that what they are doing is dangerous. Using color tape to designate boundaries on carpets, floors, or walls can help to visually remind children where they need to remain.

12. Secure Eating Utensils and Place Settings

When using spoons or forks during mealtimes, consider securing them in your child's hand by tying them with cloth. Children may "unintentionally" throw forks across the table and injure other family members. If the child throws or sweeps plates, bowls, and cups, secure them with adhesive Velcro and attach them to a secure placement. Use non-toxic, high quality plastics (for example, Tupperware) or rubber plates, bowls, and cups to prevent shattering of breakable items.

13. Remember Fire Safety

Regarding fire safety, it is important to keep lighters and matches out of their

reach or locked up. Place safety covers over gas stoves and oven knobs so that your child cannot turn them on. Always supervise children closely when there is an active fire in the fireplace or when there is a barbecue with open flames. Many community fire departments provide stickers (called Tot finders) for bedroom windows of children, so that in the event of a fire, the firefighters can locate a child's bedroom quickly. While it may be difficult to teach an individual on the autism spectrum about the dangerous nature of fire, it may be possible to teach him or her about how to behave when it comes to fire safety.

Developing social stories (with photographs, pictures, words) about smoke detectors, fire, fire alarms, touching fire, etc., and reading out the stories to the child on a regular basis is the place to begin. In addition to social stories, the use of visuals (photos, pictures) can assist the child in understanding what they are not supposed to do and/ or what they are expected to do. For example, a "no touching the oven burners" sign could consist of a photograph of the oven burners with a bright red "no" symbol or 'STOP' sign over the photograph to visually depict the rule for the child.

14. A modified study room :

Your house should be such that it promotes learning. Your child should be able to sit and study without much distraction. These are the some environmental modifications, which will help you minimize distractions and help your child attend to his studies better to help minimize distractions and increase attention while studying.

- Have a set time or routine for his homework or studies.
- Establish a specific area where the child does the homework every day-away from noisy siblings and other people who may distract him.
- If your child is using the computer for his study purpose, provide sufficient, uncluttered desktop space.
- Keep sharpened pencils, pens, erasers, and paper available in organized containers that the child would have an easy access to.
- Consider the temperature of the child's workspace.
- Provide sufficient lighting. Avoid fluorescent lighting.
- Be sensitive to the fact that the child may have his own learning style when it comes to desks, tables, and chairs. If your child is sitting on the floor or a carpet provide a clipboard or lap table.
- The area should be free from desired toys, the television, or other things that the child may find distracting or more desirable.

15. Controlling time spent on electronic items/phone :

Video games, television, and mobile phones are a big attraction for children. For some, these are almost a source of obsession. Trying to limit their time spent on

these items can often prove very difficult. Forcing them to turn them off can often lead to big power struggle and a lot of agitation. Sometimes, reinforcements may work. Devices are available to control time spent by the child in using the telephone, television or computer. These devices are hooked up to the phone jack, television, video games and computer; and they allow the parents to program how much time the child can spend on the electronic component. The electronic equipment immediately shuts off as soon as the pre-set time is over. Parental locks are also useful and can be used wherever necessary esp. for cartoon shows and channels. This would help them restrict the time spent on television.

16. Provide a relaxation room :

Sometimes autistic children become very aggressive and throw things around. Episodes of aggression can be difficult for parents to control. To avoid this you can provide a room where the child goes to stay alone and "cool down" before or during an explosive episode. This should be seen as a tool to help the child regain control, and not as a punishment. The child's bedroom may be an option. There is a drawback to such an arrangement. The child may associate the room with the behaviors and the negative feelings, and may not want to enter it on his/her own for relaxation, leisure, or sleeping. If this happens, try and use another room. When you are thinking about a relaxation room for your child, the following points should be considered:

- There should not be too many objects in the room.
- Place soft, non-breakable objects in the room.
- Replace glass windows with acrylic sheet.
- If possible fix furniture to the floor or walls so that your child does not move it and does not hurt him or herself while moving around the house.
- Have a big bean bag, soft mats, big cushions and pillows, or a soft bed for the child to relax on.
- Use long curtains instead of blinds. These can be hung with Velcro instead of curtain rods.
- Have soft sensory items that the child can use for calming him/ herself.
- Have a music player that can be used to play calming music.
- Instead of bright lights use calming Christmas lights, fiber-optic lights, lava lamps, and aquariums.

17. Consider options for identification :

It is important that your child has proper identification in the event that he or she runs away or gets lost and is unable to communicate effectively. Once a child with ASD becomes mobile, he/she may wander out of the house without supervision. Children on the autism spectrum often like to be outside and roam about. So leaving the home to go outside is common. Once outside the home, the child is vulnerable



Figure 34.6 : Child's Identification Card

and may be unable to get back or communicate to others about where they live. You could have them wear an identity card or you could write the home address on a paper and put it into their pocket or bag.

Other Considerations :

- Be sensitive to the fact that children may find the odors of some foods to be aversive when being cooked.
- Children can also have aversions, sensitivities, or allergies to certain perfumes. If so, avoid using bathing soaps, shampoos, and lotions with strong fragrance.
- For children with sensitivity to sound, use carpet instead of hardwood floors.
- Adjust the water temperature of the heater so that the child cannot burn himself by turning the hot water on.
- Replace the open-lip bottles of shampoo for ones with pumps on them to make it more difficult to ingest large amounts.
- Use 'STOP' signs on doors, drawers, furniture, and appliances to help children understand that these items/areas are off limits.
- Experiment with a variety of music. Music can affect the child's moods. It can also be used to stimulate or calm the child.

Once general safety, good judgment, competence and understanding of what is expected can be demonstrated by your child, many of the environmental modifications can be removed over time. Introducing the above suggested home modifications and intervention techniques will not only help to keep your child and your family safe, it will also ensure that your child is learning and utilizing his or her full potential towards leading an independent life.

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SUMMARY :

Your child's hyperactivity, poor speech, sensory problems, inattention, etc., are often your everyday concerns. But the larger picture including your child's education, job prospects, future security, marriage, etc. is the major concern.

- Basic education for your child is mandatory. Obtain all the necessary information about schools, curriculums and provisions for your child in your vicinity. Schools must provide accommodations to include children with autism into mainstream schooling. Teachers should train themselves and adopt teaching methods to facilitate their learning.
- Plan for their careers in advance by keeping in mind their skills and interests.
- Begin teaching your child about sexual identity, menstruation, masturbation, sex and safety at the right time.
- Plan for your child's marriage rationally, with a clear idea about the reason for marriage. Seek guidance from a professional.
- Educate yourself about all the laws protecting the rights of an individual with autism.
- Prepare yourself, the child and family members for emergencies like seizures, wandering away, uncontrollable aggression, etc.
- Modifications at home and assistive devices will help the child function better and independently.
- Delve deep to understand your child and his/ her exceptional world. Develop their strengths.
- Take sufficient care of yourself too. Keep yourself emotionally and physically fit in order to provide the best care for your child.



SECTION G

The Bigger Picture

37. A Peek Into Their Extraordinary World....

Autism is an elusive disorder. The only thing consistent about autism seems to be its inconsistency. What makes it more puzzling is that no two or twenty persons with autism are alike. It must be understood that these are a spectrum of disorders and each child could lie anywhere within this broad spectrum. That is what makes each child's symptoms, traits and behaviors exclusive and baffling. An insight into their out-of ordinary world, their viewpoint on our so called "normal" world and the cause and effect of their behaviors could really make the child's life and yours' much easier and meaningful.



To begin with, let us try and logically reason out why they are, the way they are....

Imagine a person with motion sickness forced to sit on a roller-coaster ride. If you are someone who suffers from motion sickness or vertigo you could surely imagine the nauseating feeling, the fear and anxiety that surface even before the ride begins. These problems are found to be associated with disturbances or hyper-sensitivity of the

vestibular system (canals in the inner ear that detect even slight body movements). Such intense discomfort and agony can be caused by the dysfunction of one system alone. Now, try and contemplate the degree of distress a person with autism undergoes when all his input systems, viz., hearing, smelling, touch, balance, seeing, etc, (auditory, olfactory, proprioceptive, tactile, vestibular and visual) are constantly in a state of high alert. So, why are all the common environmental inputs so alarming and threatening to these children? The blaring horns of cars in traffic, the smell of a particular flower, touch of other people, the movement felt when on a swing and the sight of multiple colorful objects lined up at the supermarket are just a few examples.

The most widely accepted explanation for these perceived threats are the sensory processing problems seen in these children (as also explained in chapter of occupational therapy). In addition to these, impaired speech and language skills, intangible social interaction skills and a poor concept of 'self' are some of the other underlying fundamental problems in these children.

As an onlooker, we would always see these children to be "autistic" due to these root problems that project as obvious behavioral abnormalities. Let us for a moment put ourselves in their shoes. How would we want to be looked at, treated and addressed? For instance, if you are suffering from obesity or diabetes, would you be alright with people calling you obese/fat or a diabetic? That is not all that you are. Each individual has several other characteristics and abilities that determine who and what they are in life. So, why call these children "autistic"? The point is not to label them. They are just like other kids. It is just that, they "have autism".

These kids seem oblivious to the happenings around them. Their introvert behavior (in their own world) and lack of verbal interaction gives us no right to assume that they are unable to listen to or are inattentive to our conversations. Probably the child thinks in his head- "I can hear and understand everything you are talking about me. In fact, my heightened sensitivity to auditory stimuli makes your conversations loud and clear to me. Your statements about my strange behaviors and inabilities are only going to reinforce them and further lower my self-esteem". Pin pointing their difficulties and inabilities to others, in front of them may not be a good idea. Also, it is very important to them that we understand that their inabilities are not their fault. The child is not intentionally ignoring your commands or socially isolating himself. One must understand what the child is trying to convey; i.e. "I can't do this" and not that "I won't do this".

Speech and meaningful conversations are definitely an issue and the child is aware of that. Their behaviors are their only tools for communication. Do not reprimand them for their hand-flapping, for pacing up and down or for crying out loud. Do not treat their behaviors as an embarrassment to you. Try and keenly observe and interpret them. Give them the liberty to explore their modes of expression. Noting down and keeping a log of their behaviors will help you deduce a pattern. Keep an eye out for their facial expressions, physical activity levels, sounds, silence, etc. You will slowly be able to understand all their indirect messages to you.

Play the role of a facilitator. Do not assume that your child does not want to play with other children his age. He'd probably want to, but he may just not know how to initiate it. Request other children to welcome him/ her. Help them exchange communication with your child and back. Intermittent cuing will help your child understand what he is expected to do, how he must interact and play. Thank the other children for accommodating your child.

Being an integral part of the child's world is essential. Spend quality time with your child every day. Since they find it difficult to step into your world, venture into theirs'. Interact with them through simple, structured conversations on subjects that interest them. Connect with your child and identify all his specialties and positives. Do not approach your child with a "why can't you sit steady for at least five minutes?" attitude. Approach them with a "how amazing are you at solving puzzles!" attitude.

The glass half-full...

While there is sufficient focus on the symptoms, problems and impairments seen in children with autism, we believe that it is important for you to identify their positives. The special traits of those with autism are the highlights of their personality and identity in our society. Identifying and nurturing them will make their existence more meaningful, provide a base for a productive future and will keep you motivated throughout the journey.

Individuals with autism, rarely lie. As normal beings though, we may try to stand by the truth, we may occasionally be forced to lie. On the other hand, for those with autism the false is clearly differentiated from the truth. So you can take your child's words for the truth. When your child reports that he got beaten up by another kid in school, never mistake it for a lie or a made up story. Address his problem seriously.

Looking beyond surface qualities and never being judgmental are typical of those with autism. They do not base their opinions on things like who is fatter, smarter, richer, etc. They are actually capable of understanding the real personalities and traits of other people. Also, many of them are less materialistic as compared to their "typical" peers.

Choices and preferences are clear to them. They need not do something or like something because they are expected. For those with autism, social expectations and obligations are of little importance. What you see is what you get. They will not pretend to be good at a sport or enjoy a movie, just because they wish to please someone or want to fit in. Added to this, these individuals do not involve themselves in mind games or hidden agendas.

The presence of a person with autism changes one's life. Their presence may have definitely changed your outlook towards life. Having such a person in our lives has had a profound positive impact on our perceptions, beliefs and expectations. As parents you must learn to emphasize on these riches.

Two sides of the same coin...

- Memorizing the states in order takes 10 minutes. Packing a school bag takes hours together.
- It's easy to recite an entire poem but difficult to make up a story.
- It's easy to line up toys but difficult to stay in line.
- It makes perfect sense to climb on the sofa but little sense to sit on it.
- Family pictures on the wall are boring but that speck of dirt next to it is extremely intriguing!
- Focus on spinning objects can be sustained endlessly. Focus on homework cannot exceed three seconds.
- Called by name - can't hear a bit. Some dog barking at the distance - clear as a bell.
- How to operate the remote control or a computer requires zero instruction. How to button up pants needs intensive instruction.
- Navigating social rules is just too difficult. Navigating from the back seat of the car - highly skilled.

Savant syndrome :

Savant syndrome is a frequently talked about phenomenon in autism. Savants are people who have quite remarkable and often spectacular talents, despite having serious mental or physical disability. (Dave Hile's - savant syndrome) There is a common association made between savants and autism, especially after the famous 1988 film "Rain Man" based on the real life savant Kim Pee (who was later confirmed to not have autism). According to Treffert DA, savant syndrome is a rare but extraordinary condition in which persons with serious mental disabilities, including autistic disorder, have some "island of genius" that stands in marked, incongruous contrast to overall handicap. The savant skill is said to be an exceptional ability, which the otherwise 'neurotypical' (normal) individuals are incapable of.

A common misconception these days is that all those with autism have savant abilities. Studies have reported a presence of 1% to 10% of savants among those with autism. One in ten persons with autism is the most widely accepted prevalence of savant syndrome. Just like autism is seen more commonly in males, savants are also more widely found among males as compared to females. Most of these individuals with autism and savant abilities have an IQ of 40 or above.

What are the commonly noted savant skills?

The savant skills are typically seen occurring in a narrow spectrum of abilities. Whatever the skill it is always linked to their unique memory capacities. A prodigious memory is

integral to these skills and is common to all savants. Considering all the abilities in the human repertoire, it is interesting that savant skills are usually found in 5 general categories:

- Memorization - superior memory is a common feature of savant syndrome, but it also can be a special skill in its own right. There are cases of savants who have memorized population statistics, telephone books, bus schedules, and in one remarkable case the 9 volume edition of Grove's Dictionary of Music and Musicians (The Walking Grove, Sacks, 1986).
- Lightening calculation - this is exhibited in the instantaneous calculation of multiplications, square roots, etc, the determination of prime numbers. (The Twins, Sacks, 1986).
- Calendar calculating - often involving the ability to identify the day of the week upon which a particular date falls, in one case any time in the last, or next, forty thousand years!! (The Twins, Sacks, 1986).
- Musical ability - this is a relatively common savant skill, the co-occurrence of musical genius, blindness and learning disability is a striking feature here. Savants will have perfect pitch, and can play a complete piece of music after hearing it only once (see Hermelin, 2001).
- Artistic ability - not as common as musical abilities, but there are savants with exceptional painting, sculpture and especially drawing skills. e.g. Nadia (Selfe, 1977) and Stephen Wiltshire (1987; 1991; see also Sacks, 1995; Hermelin, 2001). See also The Autistic Artist in Sacks (1986).
- Language ability - this is fairly rare, but there is one well documented case of a savant with CNS damage since birth who could read write and translate 15 to 20 languages (Smith & Tsimpli, 1995; Hermelin, 2001). Hermelin also includes a case of a savant poet.

Other skills that have been reported less often include prodigious language (polyglot) facility; unusual sensory discrimination in smell, touch, or vision, including synesthesia. Synesthesia is a perceptual condition of mixed sensations: a stimulus in one sensory modality (e.g., hearing) involuntarily elicits a sensation/experience in another modality (e.g. vision). Likewise, perception of a form (e.g., a letter) may induce an unusual perception in the same modality (e.g. a color). Perfect appreciation of passing time without the benefit of a clock or knowing what activity is to be performed when is yet another skill. Knowledge in specific fields such as neurophysiology, statistics, or navigation has also been reported.

How do savant skills develop?

Skills enlisted above are characterized as non-symbolic, concrete, artistic and direct. The right hemisphere (half) of the brain is said to be responsible for such functions. A recent finding provides the possible explanation for savantism. In autistic disorder, left

brain dysfunction, compared to right brain activity, has been demonstrated in a number of studies. In an attempt to compensate for the left sided deficits, the right brain is believed to over-function, leading to exceptional abilities in concrete tasks like calculations, playing instruments, etc.

Single-photon emission computed tomography (SPECT) of a 9 year old savant with autism studied by Miller et al., showed bilateral increased frontal perfusion with bilateral anterior temporal lobe hypoperfusion, which was worse on the left than on the right. These researchers concluded: "The anatomic substrate for the savant syndrome may involve loss of function in the left temporal lobe with enhanced function of the posterior cortex." Thus the right brain compensates for the left brain's hypo-function as a result of brain damage.

Some believe that there is a specific gene responsible for developing savant skills. Nurmi and colleagues divided their study group into "savant skills positive" and "savant skills negative" families. Study of the "savant skills positive" subset yielded significantly increased evidence for linkage to 15q11-q13.

Several theories continue to emerge in order to explain the occurrence of the Savant Syndrome.

Some famous "autistic savants"

- Gottfried Mind- Was an autistic savant who was a gifted painter. He created many paintings of animals.
- Alonzo Clemons- An American clay sculptor
- Tony DeBlois and Leslie Lemke - Are blind American musicians
- Temple Grandin is an Associate Professor at Colorado State University and a famous and successful adult with high-functioning autism. Her writings on the web are widely read and quite inspirational.
- Stephen Wiltshire- An accomplished architectural artist
- Henriett Seth F., is an autistic savant and is gifted with exceptional artistic abilities. She is also an accomplished writer. She is one of those few female savants.
- Matt Savage is an autistic savant with excellent musical abilities.
- Jonathan Lerman- An American artist
- Jerry Newport is an author, savant, and has Asperger's. His wife, Mary Newport, is also a savant on the autistic spectrum.
- Derek Paravicini is another blind musician from Britain
- James Henry Pullen - A gifted British carpenter



As parents and teachers dealing with children with autism each day, you may be constantly reminded of their problems and limitations. Ensure that you focus on the small positives and the specialties to ease yourself and motivate your kid. Remember the key word is "PATIENCE".

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38. Sexual Aspects

Sexuality is an integral part of one's personality. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life. Sexuality is not synonymous (same as) with sexual intercourse. "Sexuality influences thoughts, feelings, actions and interactions, and thereby our mental and physical health" (WHO, 1975).

Unfortunately, even today there are many myths that the society in general believes about people with autism. Some believe that individuals with autism have little or no interest in sexual activities while others assume that they are hypersexual.

What is the Truth?

Research has found that many individuals with autism, desire social contact and sexual intimacy. Despite having sexual and social desires, individuals with autism find it extremely challenging to develop and maintain these relationships. Those with high functioning autism are comparable to the average individuals. They may attempt some form of social contact but they too have difficulty in developing friendships and relating to others. Casual interaction also is a problem as they are unable to experience the joys which come from meaningful social contact and hence they face loneliness.

Sexuality, sexual desires & behaviors, unlike other areas of development, correspond to the chronological age of the child and NOT the developmental age. Thus, even though your 13 year old child may have an IQ equal to that of a 2nd grader, his sexual & physical development would be age appropriate.

Due to the lack of social competence some of them may engage in inappropriate sexual behaviors. For example an individual with autism may lack appreciation of social boundaries by not seeking privacy for activities such as masturbating, undressing, using the toilet and bathing. Individuals with autism also lack knowledge regarding issues such as sexual hygiene, physical changes during puberty, sexual behaviors, the reproductive process, birth control, sexually transmitted diseases, and acceptable behaviors towards a person of romantic interest.

Sex Education :

Some parents feel that it is of less importance to teach young adults with autism about sexuality. It is wrong to assume that sexuality is unlikely to become a part of their lives. It is also crucial for individuals with autism to understand the difference between appropriate and inappropriate behaviors, and to distinguish between the various types of healthy relationships. This is where sex education plays an important role. Every child nearing puberty must be provided with sex education and for those with autism education must be more specific and thorough. Sex education is a life-long process that encompasses many aspects like: the biological, socio-cultural, psychological and spiritual dimensions of sexuality. The goals of sex education are as follows:

- Human growth, development and puberty
- Masturbation and menstruation
- Sexual abuse and personal safety
- Social skills and relationship building
- Dating skills
- Personal responsibility and values
- Pregnancy, childbirth and parenthood

What to teach your child and When?

Most parents wonder when to begin discussing about puberty with their child. It is important to realize that children with autism often need a longer time to adjust to and understand any changes in their lives. Therefore, you will need to decide how much preparation time your child needs. You may want to consider whether a particular behavior or habit needs changing, for example, if your child undresses himself/ herself at unexpected and inappropriate situations. It is helpful to train for and adopt socially appropriate behaviors before entering puberty.

You may wonder, "How could she have already started having her periods earlier than other?" You need to understand that all children go through puberty, regardless of their IQ or social skills. The brain does not tell the body to stop growing/ maturing if the boy or girl's developmental level is lower than his/ her actual, chronological age. Puberty is a stage of development. Puberty is considered to begin around the age of 12 years for girls and the age of 14 years for boys. The physical changes of puberty center around the development of a secondary characteristics (facial hair, breaking of their voice in boys and development of breasts in girls) and the onset of menstruation (in girls) and ejaculation (in boys).

Teach the following during childhood years:

Difference between boys and girls	Difference between public and private
Basic facts of body parts	Introduction to puberty (physical changes)
Menstrual care	Good touch v/s bad touch

Teach the following during adolescent years:

Puberty and menstruation	Ejaculation and wet dreams
Masturbation	Pregnancy, safe sex and birth control
Attraction and sexual feelings	Restroom use
Relationships and dating	Personal responsibility and family values
Love v/s sex	Sexual preferences
Laws regarding sexuality	

How to teach your child?

Use of language when you are educating your child: You need to be careful about the use of appropriate language, particularly if your child is very literal, for example, you may naturally describe your son's voice as "breaking", but this could be highly worrying for a child with autism. You could use simple language instead; for example, say "Your voice is changing and likely to become deeper." You could then tell them how their uncles and brothers voices have also changed.

Never use abstract language to convey information. Children with autism do not follow abstract (vague, with hidden meanings) concepts. Hence you must use concrete words like 'penis' and 'vagina' and not "birds and bees" while educating them about reproduction etc. They also need to be explained about the physical changes that take place in their body such as menstruation or erections and wet dreams. Your child may need reassurance that these occurrences are normal processes within the body and that every one of their gender experiences similar changes. Make sure your language conveys that there is nothing to be scared or anxious about and that you will be supportive throughout the process.

- Masturbation :**

Masturbation is a natural activity for a child who is going through puberty. Be prepared to talk about masturbation with your child so that they do not develop any anxieties about what they are doing. When talking to your son about erections, you will also need to explain to him about wet dreams. You could explain this with the help of sex education books. It is also important for your child knows

how to clean himself after masturbation. This includes teaching them how to use tissues/wet wipes or a towel and washing himself well.

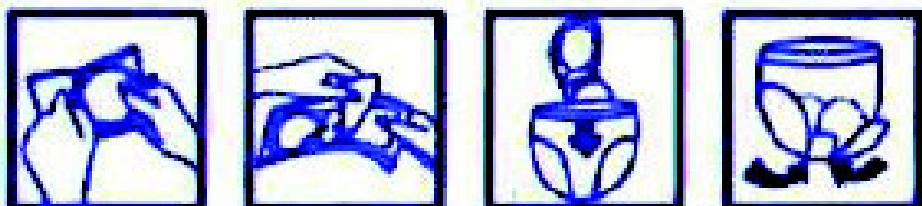
- **Menstruation :**

In girls, physical changes usually begin between ages 7 and 14 years. Girls begin to develop breasts, pubic and underarm hair and have vaginal discharge. A girl's menstruation (period) usually starts within a year or two after these changes. The average age a girl starts menstruating is around 12 or 13 years but some girls start as early as 9 years and others may be as late as 17 years. It becomes increasingly important to have good hygiene by taking a shower or bath each day, washing the underarms and vaginal area well.

How could you teach your girl child about menstruation and its management?

The following strategies may be of use.

- Put red food coloring in her underwear to show, what the blood might look like when her periods would start.
- As her mother you may model a few steps to wearing and changing sanitary pad for her.
- The color of the pad and the panty should be different clearly identify where the pad should be placed on the underwear.
- Do not expect your daughter to understand the different types of sanitary pads. You may need to provide her with a pad which would be appropriate for her i.e., the size that suits her best, with wings or without, thickness, etc. Too many pieces of information could be confusing, hence pick what is appropriate for your daughter and teach her only that.



Steps to use a Sanitary Pad

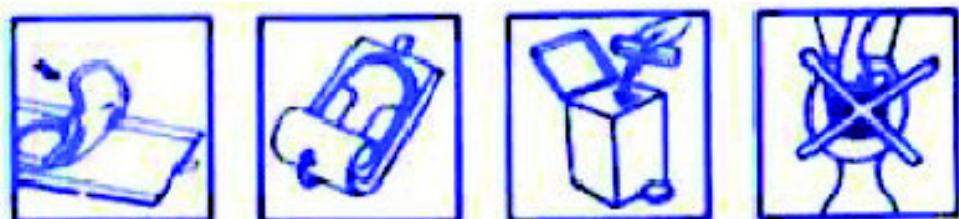


Figure 38.1 : Disposal of Sanitary Pad

- Make a visual schedule about the changing time i.e. how many times in a day she needs to change her pad. Also, keep in mind the school schedule. She should be taught that she could change her pad during the break time. Try to keep the school and home schedules the same.
- Teach her ways of disposing the sanitary pad after usage. Use a step-by-step method of demonstration and practice.
- If the child is having difficulty learning the above mentioned strategies then break it down in steps and explain. Also, mock practice sessions are very important as it will prepare your daughter well in advance.

What are the practical strategies you could use while educating your child?

- Think ahead i.e. start teaching the child before puberty sets in.
- Be concrete (talk about the penis or vagina, not the birds and bees)
- Practical programs on sex education which focus on obvious topics such as identification of body parts, dealing with menstruation or masturbation, personal hygiene and appropriate social behavior (ranging from how to relate to strangers and familiar adults to dressing appropriately) must be incorporated.
- Sex education should be taught to individuals with autism using anatomically correct (human) dolls and not toy dolls, because that could lead to unclear ideas about the human body. Also, sex education books could be of great help.
- Social skills training for an individual with autism is required to develop healthy relationships. These skills could help them understand how to initiate a conversation, maintain relationships and find their life partner. Skills necessary for successful social functioning are learnt before they are practiced in natural social situations.

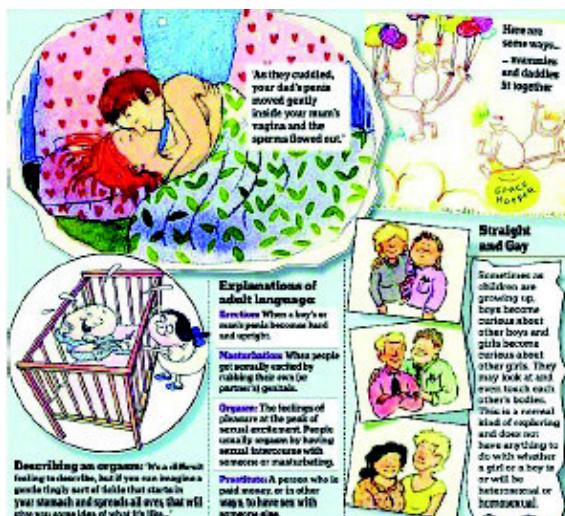


Figure 38.2 : Sex Education

- Be consistent and repetitive in educating them about sexual safety measures.
- Find someone of the same gender to teach the basics about safety and hygiene.
- Strongly reinforce all appropriate behaviors, for example, if the child closes the door while using the washroom, acknowledge it and reward him for his positive behavior.
- Redirect inappropriate behaviors. For example, if a child is likely to masturbate in class or in public, give him something to carry or hold which could re-direct his focus.
- Group sessions on social skills could include various activities; for instance, a discussion about specific behaviors (e.g., communication and body language) or a demonstration of inappropriate behaviors followed by identification of the errors. This could help the individual with autism gain practical exposure.
- It is very important to pay detailed attention to personal hygiene, especially during puberty. Children with autism will need to be made aware of appropriate solutions such as using deodorants, showering and washing their hair more frequently. These processes will have to be explained as well as demonstrated to them.

How to ensure personal safety and prevent sexual abuse?

Persons with autism are vulnerable to sexual abuse. Along with family members and friends you should protect your child from being victimized. Though there is no sure way to do so, some of the following tips may be helpful in protecting your child from sexual abuse:

- Teach your child actual names of private body parts.
- Avoid focusing only on "stranger danger." Keep in mind that most children are abused by someone they know and trust.
- Teach them about body safety and how to differentiate between "okay" and "not okay" touches.

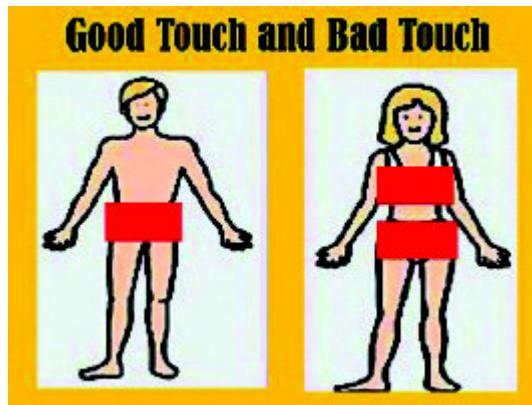


Figure 38.3 : Areas of Bad Touch are Highlighted

- Make sure your child knows that adults and older children never require help with their private body parts (e.g., bathing or going to the bathroom).
- Let your child know that he/she has the right to make decisions about his/her body. Empower them to say "no" when they do not want to be touched, even in non-sexual ways (e.g., politely refusing hugs) and to say "no" to touching others.
- Teach children to take care of their own private parts (i.e., bathing, wiping after bathroom use) so they don't have to rely on adults or older children for help.
- Educate children about the difference between good secrets (like surprise parties which are okay because they are not kept secret for long) and bad secrets (those that the child is supposed to keep secret forever, which are not okay).
- Trust your instincts! If you feel uneasy about leaving a child with someone, don't do it.

The best time to talk to your child about sexual abuse is NOW. Along with other family members and friends, you could protect your loved ones by learning certain signs that may indicate victimization. It is important to remember that each person is different and can show different symptoms. Take it very seriously when your child reports sexual abuse by a parent or another adult caregiver. Recognizing possible signs of abuse can help you to assist the victim in getting help and stopping the abuse as soon as possible. The following are some behaviors common to children who have been abused:

- An increase in nightmares and/or other sleeping difficulties
- Anger outbursts
- Anxiety/Depression
- Difficulty in walking or sitting
- Withdrawn behavior
- Pregnancy or contraction of a venereal disease, particularly if under age 14
- Propensity to run away
- Regressive behaviors depending on their age (e.g., return to thumb-sucking or bed-wetting)
- Reluctance to be left alone with a particular person or people
- Sexual knowledge, language, and/or behaviors that are unusual and inappropriate for their age

All the above guidance, signs and strategies should be able to reduce the anxiety of parents with respect to the sexual problems faced by their children suffering from autism. The parents should be able to handle any of the mentioned issues, thus empowering the child and making them independent. It has been observed that high functioning autistic people have normal family and sexual life, when given proper and adequate guidance.

"By starting early, providing positive messages about sexuality...individuals with ASD's will have the opportunity to develop a positive sexual self-view, build confidence and self-knowledge, avoid potentially dangerous situations for themselves and others, and seek the sexual well-being that best meets their needs and desires." (Byers, S., Nichols, S., Voyer, S. & Reilly, G. (2012). Sexual well-being of a community sample of high functioning adults on the autism spectrum who have been in a romantic relationship. *Autism*. Advance online publication. DOI: 10.1177/1362361311431950.)

"..Individuals with autism are sexual; they are interested in sexuality, have sexual needs, and oftentimes want to develop relationships with others. Moreover, individuals with autism display a wide variety of sexual interests and behaviors. In other words, sex matters." (Gougeon, N. (2010). Sexuality and autism: A critical review of selected literature using a social-relational model of disability. *American Journal of Sexuality Education*, 5, 328-361).

References:

1. Chan, J. & John, R. (2012). Sexuality and sexual health in children and adolescents with autism. *The Journal for Nurse Practitioners*, 8, 306-314.
2. Byers, S., Nichols, S., Voyer, S. & Reilly, G. (2012). Sexual well-being of a community sample of high functioning adults on the autism spectrum who have been in a romantic relationship. *Autism*. Advance online publication. DOI: 10.1177/1362361311431950
3. Gougeon, N. (2010). Sexuality and autism: A critical review of selected literature using a social-relational model of disability. *American Journal of Sexuality Education*, 5, 328-361

39. Protection Under The Constitution

What are the government provisions and laws that protect the interests of individuals with autism?

In India :

Primarily as a result of years of intense work by several organizations and concerned bodies with the Ministry of Health, the Government of India now recognizes autism as a disability. This development is relatively recent. Formerly, schools catering solely to persons with autism 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, though in reality persons with autism may not be mentally retarded. Through the commitment of a community of parents, siblings, relatives, and people with autism themselves 'autism' now has a place for itself in the disability legislation and movement in India. You must continue to educate yourselves 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 these children. Some of the Acts protecting individuals with autism are outlined below.

- The Right to Education Act (2012) mandates that all children have a right to attend the neighborhood school. The Sarva Shiksha Abhiyan (SSA) which is the vehicle for the RTE ensures support to children with Autism, through the resource teachers, teaching aides. In many states, students with autism get a one on one support with care giver or aide in the classroom. It provides for accommodations to help the child integrate into main stream schools.
- In March 2008, the "Niramaya" scheme was launched to provide affordable, government sponsored health insurance plan for people with autism, mental disorders and multiple disabilities. It was conceived with the following objectives:

- To provide affordable Health Insurance to persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities.
- To encourage health services seeking behavior among persons with disability.
- To improve the general health condition & quality of life of persons with disability.
- In November 2007, the Reserve Bank of India (RBI) made it easier for persons with disabilities like autism and cerebral palsy to open and operate accounts, by asking banks to accept guardianship certificates issued by local level committees set up under the National Trust Act. The RBI Notification Banks are advised to rely on the guardianship certificate issued either by the district court under the Mental Health Act or by the local level committees under the National Trust Act for the purposes of opening and operating bank accounts.
- National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act (1999), provides for constitution of the Board of the National Trust, Local Level Committees, Accountability and Monitoring of the Trust. It has provisions for legal guardianship of the four categories of the persons with disabilities and for creation of enabling environment for their as much independent living as possible.
- Under the Income Tax Act, 1961, as amended by Finance Act, 2007, there are tax benefits available to families of children with autism. You must have a certificate of autism in order to qualify for these benefits.
- Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (1995), gives effect to the proclamation on the full participation and equality of the persons with disabilities in the Asian & Pacific Region and provides for their education, employment, creation of barrier free environment, social security, etc

In the United States of America :

The diagnosis of children with Autism Spectrum Disorders (ASDs) in the United States is becoming an increasingly common occurrence. Public health officials, researchers, state and federal policymakers, and consumers have mobilized resources in an effort to understand and ultimately reverse this disturbing trend. Several laws have been enforced to help those with autism lead more independent and honorable lives. Every American citizen is protected under the constitution, and special laws have been enacted to protect people with autism and other disabilities. These special laws are for the protection of the disabled and to provide better opportunities for everyone. There are no exceptions; everyone is protected under these laws regardless of disability, gender, ethnicity or race, making the opportunities of life better for everyone.

- The Combating Autism Reauthorization Act of 2011 was signed in by President Obama. This act continues its important investments in research, early detection and supports and services for both children and adults on the autism spectrum. It

has also reauthorized the Interagency Autism Coordinating Committee (IACC). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

- All 50 states have laws related to autism, which vary in scope and subject.
- Some states include autism in the definition of "disability" or "developmental disability." Others have created centers, councils, pilot programs, commissions or institutes for the study of autism.
- States like California, Louisiana, Maine, Montana, New Hampshire, New Jersey, South Carolina and Virginia require insurers to offer or provide coverage for autism diagnosis or treatment.
- Resources from the federal government are available to assist concerned communities, families and caregivers as they support children with ASDs.
- Children with autism who are eligible for Medicaid may receive services through the Early and Periodic Screening, Diagnosis & Treatment program
- The "Individuals with Disabilities Education Act," (I.D.E.A.) covers all individuals from age three to twenty-one years and provides autistic children with special education programs. The I.D.E.A. gives parents the right to be involved in educational decisions for their child. The school district must have the child assessed by a private professional to qualify under the I.D.E.A., for placement in the appropriate school. This law gives the rights for your child to receive a free public education based on their skill level.
- If the public school district does not have a program available for these children, they are required by law to either find a school with the needed program or to create one without cost to the parents or guardian of a child with autism.
- The American Disabilities Act prohibits discrimination in the work force due to disability including state and local government, public accommodations, the United States Congress, public transportation, and telecommunications. Therefore if a person has autism, they cannot be refused the job if he has the skills to do it.
- Other laws provide rights for people with disabilities to be constitutionally equal to others, allowing them the right to vote. The polling places must make easy access and other needed accommodations for them.
- Another law protects individuals with autism from being refused housing based on their disability; this includes health care institutions and providing equal rights in all other aspects of life.

You must be well versed with these provisions to help your child to the maximum.

Future...

India: Ministry of social justice and empowerment drafted a New Legislation for PWD:

The rights of PWD Bill 2011, replacing the present PWD (equal protection of rights and full participation) Act, 1995. This bill is more inclusive on the line of international conventions, which is yet to be passed and enacted upon.

References:

1. http://www.hhs.gov/autism/factsheet_autism_support.html
2. <http://www.socialjustice.nic.in/policiesacts3.php>

40. Preparing For Emergencies

Parents, teachers, caregivers and all other individuals who interact with a child with autism on a daily basis, must be aware of all the possible emergencies. You must educate yourself and others about the possible situations and means of handling them. Safety of your child is your utmost priority. Hence preparing for any untoward emergencies is a wise option.

Also, preparing your child is equally important. Children with autism may not be able to deal with the situations like going to a hospital, being assessed by a nurse or doctor, having wounds bandaged, etc. They may be extremely aversive to these sensory inputs, making management even more challenging.

What are the possible emergency situations for a child with autism?

The most probable emergency situations with respect to a child with autism are:

- First episode of seizure or a seizure lasting longer than five minutes
- Uncontrollable behavioral problems, increased agitation or aggression (which may lead to injury like fractures or any external injury).

How should you prepare for such emergencies?

- Preparing or purchasing a first aid box is the first and foremost step. Keep a first aid box (comprising items like cotton, band-aid, ant-septic cream, etc.) at an easily accessible place at home, in your car, purse, etc. These will come handy to manage minor injuries
- Undergo proper first-aid training to be able to provide appropriate aid for your child. Your local doctor can help you with the training. Arrange training sessions for your neighbors, family friends and teachers.
- Read books/picture books to your child about visiting to the hospital. Examples of books include Maggie and the Emergency Room, My trip to the Hospital.
- Familiarize your child to the procedures of first-aid. Introduce him/ her to all the materials and equipments. Dry-run medical treatments so that your child is well

prepared for the variety of sensations and does not resist during actual procedures. Pretend play games like "Doctor-Doctor" will make them aware of the procedures like stethoscope placement over the chest, feeling for the pulse, cleaning of wounds, dressing and undressing , etc.

- Make him practice staying still for 10 seconds, while he has a pretend X-ray. Add this in all his play activities, like playing statues. Add positive reinforcements when the child achieves the task.
- Keep it positive: Whenever you speak of doctors and hospitals to your child, talk to them in a favorable way. Tell your child how they make us feel better.
- Through books, pictures and video CDs, explain to your child what is done during different medical procedures and what they feel like.
- Familiarize your child with doctors and nurses in the emergency room at the your nearest hospital. Ensure that your child gets comfortable with them so that during an emergency he/ she would co-operate with them for treatment.
- Take your child to visit a hospital occasionally. This will orient him to the environment and desensitize
- Create an autism ID card for your child. Write down an ICE (in case of emergency) contact number on the card. This will help trace your child back to you in case he/ she wander away or gets lost.
- Include an information card in all the first aid boxes and kits. This would come handy and useful in any episode of wandering of the child and should be distributed to neighbors, family, friends, teachers and all those who are in the loop of the child. The card/information booklet should include the name of the child, a recent photograph and physical description including height, weight, hair and eye color, any identifying scars/ marks, Names address and phone numbers of parents, caregivers, and other emergency contacts. Favorite attractions/locations where the individual may be found, Method of communication, if non-verbal sign language, picture boards, written word.
- Make a brief visit to your neighbors and introduce your child/adult with autism or their photograph. Give them a simple handout with the individuals name, your name, address, and emergency phone numbers. Ask them to contact you or the given numbers in case they see your child alone outside home. This approach might be a good way to avoid problems and will let your neighbors know the reason for unusual behaviors, that you are approachable and will not feel offended. Getting familiar with your neighbors can help in better social interactions for your loved ones with autism (Debbaudt, 2004).

What should you do during an emergency?

- Keep yourself and all others present around the child calm and composed.
- Use soft restraints that will help the child cool down. You may refer to Chapter 32 for strategies to handle their aggression.

In case of a seizure episode ensure the following:

- Move things out of the way so the child won't injure him or herself.
- Loosen any tight clothing around the neck.
- Put a pillow or something soft under the head.
- Lay him or her on one side.
- Time the seizure, i.e. record the time of onset of seizure, the frequency throughout the day and for how much duration the seizure lasted.

Call an ambulance if:

- The child was injured during the seizure
- The child may have inhaled water
- The seizure lasted longer than five minutes
- There is no known history of seizures

Ensure to refrain from doing the following :

Putting anything into the child's mouth

Trying to hold the child down

Giving mouth-to-mouth resuscitation until the seizure is over

Discuss about the emergency medications which you would require for your child with your doctor before hand. Whatever medications are needed, stock them at your home at a safe location, which would be accessible only to the parents and caregivers. Get thoroughly trained from your doctor with respect to safe administration of these medicines to your child during an emergency.

With all the above tips and proper, adequate guidance from your doctor, you will surely be able to handle any emergency situations occurring with your child, thus preventing any untoward occurrences and thus, keeping your child safe.

References:

1. <http://www.pathfindersforautism.org/articles/view/plan-your-response-to-an-autism-emergency>
2. <http://www.nationalautismassociation.org/safetytoolkit.php>

41. Providing Care For The Caregivers

Once you begin to notice minor problems or deviations in the development and behaviors of your beloved child, you would first go to your pediatrician. Based on a series of tests and assessments if your child is diagnosed with Autism or to lie somewhere on the Autism spectrum, you as parents go through a major turmoil of emotions. Proper guidance is required for you to be able to give the best for your child's future.

Not only does "autism" alter the emotional dynamics between your child and you, but it also stresses the emotional dialogues between you and your family. We believe parents and the family members require to be emotionally prepared to accept the diagnosis and to carry their child through this "special" journey. You must understand and see the "special" needs of their child with autism. Devoted support from caregivers (you and the family members) is crucial for an improved quality of life and attempting to normalize this "given" situation.

Usually handbooks cater to the needs of the individuals with Autism and very often the needs of the caregivers are overlooked. Due consideration needs to be given to the caregivers emotional, mental and physical health. Parents with autism usually face a lot of anxiety, stress, and also find it physically taxing to keep their hyperactive child engaged.

What are the signs of stress that a parent could undergo?

- Feeling tired throughout the day.
- Sleeping for more or less time and feeling drowsy during the day.
- Not taking proper care of oneself i.e. putting on too much weight or losing weight drastically.
- New or worsening health problems
- Loss of interest in activities or situation in which, one was interested in before.
- Undergoing behavioral and emotional changes like increased irritability, anger issues or frustration.

- Unable to, think clearly or take proper decisions.
- Substance abuse, like excessive smoking, drinking.
- Due to behavioral and emotional changes, overall negative changes in the family dynamics.

Signs of Caregiver burnout :

If the signs of caregiver stress as mentioned are left unchecked, it might take a toll on your health, relationships and state of mind, eventually leading to burnout. Common signs and symptoms of caregiver burnout are:

- Your energy levels are way too low than it used to be
- Your immunity level is crashing down as you catch every other cold or flu.
- You feel completely exhausted, even after you take a break or sleeping
- You start neglecting your own needs, either because you are too busy or you don't care.
- Your life revolves around care giving, but you hardly get any satisfaction out of it.
- Even after getting enough help, you are unable to relax.
- You become increasingly impatient and easily irritable, which comes out on the person you are caring for.
- Feeling of helplessness and hopelessness sinks into you.

Once you burnout, care giving is no more a healthy option for either you or the person you are caring for. So it is of vital importance that you recognize the early signs of stress and take action before you reach the stage of burnout.

How can I accept the fact that my child has Autism?

The first question that usually arises in a parent's mind whose child is diagnosed with autism, "Isn't my child Normal?" Parents usually find it extremely difficult to accept the fact that their child has autism. The process of acceptance is painful and difficult. The following are the stages of grieving:

Stage 1: Shock :

As a parent you may be shocked, confused or overwhelming to know that your child has autism. You may initially ignore it and would consult doctors who would negate the diagnosis.

Stage 2: Sadness or Grief :

As parents usually have high expectations and dreams for their child, all of that may come down crashing after the diagnosis. There will probably be times when they would be extremely sad or may develop depression. However, there is a vast difference between

depression and sadness. Depression would be heightened and prolonged sadness. Crying is very helpful as it helps you to release some of your tensions and frustrations.

Stage 3: Anger :

Over time, your sadness could lead to being angry. Anger could be directed towards your spouse, child, friends, employees, etc. It could come out in different ways like snapping at people, overreacting at small things, shouting at people for no reason, etc. Anger is a normal and it is an expected reaction to feelings of loss and stress that comes with the diagnosis.

Stage 4: Denial :

There would be a period where you wouldn't want to believe that your child is diagnosed to have autism. During this period even after a couple of doctors reveal the facts to you about your child you may not want to hear it. Denial is a way of coping and would be a very difficult time to deal with. It is important to keep in mind that your child's wellbeing is the top most priority. Do not alienate yourself from people who are providing you helpful feedback and are monitoring your child's progress. Whether you agree or not with the information provided don't react to it instantly. Take a look at the facts with a calm and balanced state of mind

Stage 5: Loneliness :

You may feel alone and isolated. This feeling may come from the fact that you don't have the time to contact your family and friends for help or for company, or you may think that they won't understand the situation and might not be supportive.

Stage 6: Acceptance :

Acceptance is extremely difficult and accepting the diagnosis simply means that you are ready to advocate for the child. Children with autism would not experience the negative feelings associated with the diagnosis. However, parents, teachers and siblings of children with autism may process the diagnosis in a different ways and at different rates. Give yourself time as it may take time to understand your child's disorder and the impact it has on you and your family. There could be times when you may feel helpless, angry or hopeless. However, times and feelings would change as your child begins to make progress

Stage 7: Give yourself time to adjust :

Giving time to yourself is important. Be patient as it will take some time to understand your child's problem and the impact it will have on you and your family. Moments of frustration, anger, helplessness will keep resurfacing time and again. You might feel frustrated about the way your life has taken a direction, much against the way you had thought. But as your child starts progressing, a ray of hope will make you experience that it's not over.

However, it is important that the parents move on from their grieving period of accepting the fact to the well being of the child. Below mentioned are a few tips for the parents:

It is important to identify your child's strengths and limitations.

Your focus should be to maximize your child's level of independence and not focus on how to make him "normal". Don't compare him/her with other children.

Educate yourself thoroughly about his condition, as information is empowering.

What are the strategies that one could use have a balanced state of mind?

TIP 1: ASK FOR HELP :

Taking alone all the responsibilities without break or assistance/support is a surefire recipe for stress and burnout.

- Speak up: It could be very difficult to ask for help initially. However, don't hesitate to use support and it's very important to communicate what help you exactly needs. For example: Hiring a maid makes more sense than wasting time into household work, rather you could invest that time into teaching your child or may be time for yourself like exercising. It is very important that you talk about your feelings and emotions that you are going through. It is important to vent out your thoughts at regular interval of time. Especially someone who just listens could be a great source of strength.
- Spread the responsibility: try to get as many family members as possible involved. You can divide the care giving tasks, like one person can take care of the medical responsibilities, other with finances and bills etc.
- Say "yes" when someone offers a help: Don't be shy or feel awkward of accepting help. Let them feel good about supporting you. Its smart and helpful in keeping a list ready of small tasks which others can easily take care of, like picking up groceries, driving the individual to an appointment.
- Be willing to relinquish some control: Delegating is different than trying to control everything. People will be less likely positive to help you, if you micromanage, give orders for every task, or insist to do things your way.

TIP 2: GIVE YOURSELF A BREAK :

As a busy caregiver, leisure time might seem something impossible for you. But you owe it to yourself and to the person your care for. Carve some amount of time for yourself in the schedule. Give time to yourself to relax, you will be a better caregiver for sure!

- Set aside a minimum of 30 minutes for yourself: Do whatever you love, enjoy doing. Whether it is reading, playing with your dog, talking to your friends, working in the garden or knitting, do it. You will feel relaxed.

- Find ways to pamper yourself: Small luxuries can go a long way in relieving your stress. Get fresh flowers for the house; hit the spa or whatever that makes you feel special.
- Make yourself laugh: Laughter is the best medicine as it is said. A little of it goes a long way. Read a funny book, watch a comedy movie or talk to a friend who makes you laugh. Whenever you can, try to find humor in everyday situations. It will lighten up the atmosphere in and around you.
- Visit friends: if it is not possible for you to visit, invite your friends over for coffee, or lunch or dinner.
- Use school hours: Take advantage of school hours and use the opportunity to meet your relatives, family members or friends. Plan quality time together with your spouse for example; lunch with him when your child is at the school.

TIP 3: PRACTICE ACCEPTANCE :

When faced with unfairness towards our loved ones, we often ask ourselves, "Why us?" We spend tremendous amount of time thinking over it, where there are no answers to it at the end. Try to avoid the emotional trap of feeling sorry for you or blaming yourself or finding someone to blame. Instead, focus on the situation, looking for ways which can help you grow. As the saying goes, 'What doesn't kill us makes us stronger.'

- Move on: It is very important that once you get to know your child's problem you start off with the treatment. If you know that your child is engaged in meaningful activities, you will be more able to focus on moving forward. It could also give you some free time to educate yourself and help you to take care of yourself.
- Focus on things which you can control: you can't change what has occurred, but you can surely focus on the way you choose to react to problems and situations.
- Find the silver lining: Think how care giving has made you stronger in every way. Think of how it's brought you closer to the person you are taking care of. Realize how care giving has allowed you to show back your love towards them.
- Share your feelings: If you feel that you are unable to cope up with things around and your stress or anxiety levels have increased or you are starting to show depressive symptoms (like crying spells, change in sleep or appetite, loss of interest, etc) seek help of a professional. Counseling session for you or your spouse or the entire family may help.
- Refrain from exaggerating: Refrain from constantly talking about autism to your family, siblings, friends or spouse, and rather spend quality time with people around you. Be careful to not let autism consume every waking hour of your life. Everyone in your family needs support and to be happy despite the circumstances.
- Maintain a diary: Louis DeSalvo, in Writing as a Way of Healing, notes that studies have shown that "writing that describes traumatic events and our deepest thoughts and feelings about them is linked with improved immune function, improved emotional and physical health," and positive behavioral changes.

TIP 4: TAKE CARE OF YOUR HEALTH :

Think of your body like a car. With right fuel and on time proper maintenance, it will work efficiently in the long run. Neglect its upkeep and it will start to trouble you.

- Keep up your doctor's visits: It's quite easy to neglect your health while taking care of your loved ones. Don not skip your appointments with your doctor. You need to be healthy in order to keep your loved ones healthy.
- Exercise: Exercise is a powerful stress reliever and mood enhancer. Aim for a minimum of 30 minutes of exercise daily. It will boost your energy level, help you fight fatigue, and also improves your immunity.
- Meditate: try meditation, yoga, relaxation techniques, deep breathing. It will help you to relieve stress, gives you a feeling of well-being.
- Eat well: Indulge in healthy food like fruits, vegetables, whole grains. These will help you to keep yourself fit in the long run. Avoid caffeine- it gives you a quick pick up, but also runs you down equally faster.
- Don't skimp on sleep: cutting down on sleep is counterproductive. When you sleep less, your mood, energy, productivity, and ability to handle stress will suffer.

TIP 5: JOIN A SUPPORT GROUP :

You could join support groups which are for children with autism and their parents. It may be helpful to listen or talk to people who have been or are going through a similar situation. Also, support groups could be a great source of information about the services available in your area or about the new possible treatment options available. For many

LOCAL SUPPORT GROUP	ONLINE SUPPORT GROUP
<ul style="list-style-type: none"> - People living nearby meet each other weekly or monthly - You get face-to-face contact with people; chance to make new friends who live near you. - The meeting held by the local groups gets you out of the house, thus providing a social outlet and lessening the burden of isolation. - Since the meetings are held on set timings, you can carve it into your schedule. - Since the people in the support group are from your area, they will be more familiar with the local resources and issues. It will be a good platform for exchange of information 	<ul style="list-style-type: none"> - People are from all over the world having similar issues and problems, with varied thought process, with different ideas. - You meet people online, through social groups, on forums, websites, email lists. - You can get support without leaving your house, which is good for people with limited mobility, has transportation problems or stay in a remote area. - You can access the group whenever it is convenient for you, or when you need it the most in certain situations.

parents being associated to a support group could provide valuable hope, comfort and encouragement.

Local v/s online support group :

.To find a community/support group, check the yellow pages, ask your doctor/hospital, or contact the local organizations that deal with the problems of autism.

"Remember that if you want to take the best possible care of your child, you must first take the best possible care of yourself".

References :

<http://www.autismspeaks.org/what-autism/autism-your-family>

http://www.helpguide.org/elder/caregiver_stress_burnout.htm

41. A few words from some enduring parents

India

"I take pride in saying that my son, with autism, after treatment, tutors visually impaired and mute children"

Being a mother is the one of the happiest moments of one's life. It took me to a world beyond thoughts. Arrival of my baby boy was a blessing. Everyone at home was so happy. Their faces were beaming with the joy. Soon we named our baby Shantanu Deo. As he grew older, we slowly realized that our baby was not talking nor playing like the other children of his age. Something was wrong, and we wondered what? He looked absolutely fine, just like any other kid but, his behavior was very different and we knew there was definitely something wrong.

He did not play with the other children at school. It used to pinch my heart to see him lost in himself and alone. How I wished he would call out to me in his sweet baby voice, but never even did he look at us. As he grew older, he constantly wandered by himself within the house. Slowly even other children realized that he was different. They stopped playing with him. It used to hurt me deeply. His loneliness was very painful for me. Even after visiting many doctors repeatedly, there was a still a question mark in my mind about the reasons for his behaviors. It took us too long to find out the exact problem. When he was six years old, we found out that he had 'Autism'. We were completely crushed after finding out that our son cannot learn like normal children. It seemed like the end of everything and we didn't know what to do next? Every doctor we consulted had a different opinion about his problem and how to handle it? We just did not know whom to believe. We couldn't understand how to go about treating his condition?

We found out that there were special schools for children with Autism and that they can learn if taught in a special manner. This was a life altering piece of information for us. We were very hopeful that this will be a positive turn in Shantanu's life. We moved to Thane. He was admitted to a special school there. He was given special education,



acupressure and speech therapy. Slowly we could see some changes but there was still a long way to go. The therapies were ongoing but somewhere I felt that it did not bring about the change that I had expected.

Years went by and Shantanu grew older. I knew he would probably never be completely 'normal'. We were prepared to accept him the way he was. But we were determined to help him get better, to the best of our ability. We chose to compromise with our lives. We had no hope from the special education that he was undergoing. We decided to discontinue the distressing special school and teach him in a loving and nurturing environment at home. I myself took up a course to become a special educator. I began to teach him at home and he appeared for school exams externally. Now, he was getting better.



We were still looking for newer treatments for him. My father, who is Shantanu's maternal grandfather, came across an article about Stem cell therapy in a daily newspaper. We, as a family discussed about the potential of this treatment and decided to go ahead with it. We took an appointment to meet Dr. Alok Sharma at NeuroGen Brain and Spine Institute. He provided us with detailed information about this therapy and told us to be hopeful. He assured us that there would be no adverse effects and gave us confidence. He underwent Stem cell therapy after which his graph progressed upward, and much beyond our expectations. There was positive change in his behavior and speech. We slowly weaned him off his medicines. He started interacting with everyone at home, his hyperactivity reduced greatly and his understanding was getting better each day. He could read on his own, he was more attentive, could concentrate better and even his eye hand co-ordination improved. He cleared his 3rd and 5th standard (NIOS Board) by appearing for exams externally and is now appearing for the 8th standard. He is able to grasp difficult subjects like Science. He plays with my younger daughter and even takes care of her. We are all very happy now and very hopeful that these changes in him will continue. We are very thankful to the doctors.

I thank God for blessing us with a meeting with Dr. Alok Sharma at the right time. Shantanu could not even fold a small handkerchief but he now folds everyone's blankets at home. He couldn't even brush on his own but now, he can. He even bathes himself. He would earlier randomly draw lines for pictures, now he draws and paints beautiful pictures. He was never bothered about the kind of clothes that were bought for him. Now he participates in choosing his own clothes. He enjoys wearing new clothes and admires the way he looks. His understanding of things happening around him has increased a lot. He understands everything we tell him or ask him to do. He does all the small chores at home like putting the clothes for laundry into the washing machine, setting the dinner table, setting the plates, cleaning the table. He even makes tea and 'maggi' noodles on his own. He is interested in listening to music now and his music collection seems to grow every day.

I'm very thankful to the Lord for all my family members who were very considerate and understanding. They have all helped us a lot. Dr. Sharma stepped into our lives as a savior. It is only because these individuals that Shantanu has come so far. I would say that Stem cell therapy is a boon for children with Autism. When we had lost all hopes, Stem cell therapy showed us the light and filled our lives with happiness all over again.

– **Mrs. Prachi Deo**
(Mother of Master Shantanu Deo)

United Kingdom

"NeuroGen gave us a hope, that maybe something would work out differently and that is exactly what happened"



Being a mother, is the most privileged event in my life. But being a mother to a special child is a pride for me. My son Leo, who is now 11 years old, was diagnosed with Autism at the age of 4 years. It's been 7 years now since his diagnosis, and every day has brought a new challenge, a new solution and a new hope that one day everything will be fine.

When Leo was born, he had a history of delayed birth cry. Although we were a little anxious at that time, as time passed, we saw no major problems in his functions. He was bright kid with good grasping capabilities. He had started picking up words like juice, pasta and biscuit. However, when he was 2.5 years old, he regressed. His speech was the first to get

affected and eventually he stopped playing with his toys. He seemed to be withdrawing into a shell and refused to interact with anyone. He started grabbing things and throwing them around the house whenever he needed to draw attention to himself. His behavioral problems were getting seemingly difficult to handle by me and my husband. That's when we decided to sought professional help.

We met up with his pediatrician who carried out a couple of psychological assessments and evaluations. It was he, who informed us that Leo has autism. As advised by him, we enrolled Leo into a couple of therapy lessons and vocational training centers. Leo started having regular therapy sessions with speech and language, occupational therapy and psychological interventions. Although, these sessions helped him calm down to a certain extent, Leo was still facing problems with communication, social interaction and expression. This worried me deeply because at times, even we as parents failed to understand what he needed. How then would I expect my son to survive in society independently?

My husband and I, then decided that we would try and do everything we can to give our son a better life. It was then on the internet that we came across the concept of stem cells and how they can be used for autism. Further research brought us to the threshold of NeuroGen Brain and Spine Institute and Dr Alok Sharma. We sent in a detailed email about Leo's condition to a consultant at NeuroGen and we were very happy with the prompt responses we received. A couple of email conversations later, when all our doubts had been answered, we decided to take Leo to India for stem cell therapy at NeuroGen.

Leo underwent his very first stem cell session in September 2013 and yet another one in April 2014. Both times, we stayed at the Institute for a month for extended rehabilitation.

Stem cell therapy has actually been a miracle for us! Never had we expected that Leo would do well and so soon. Post stem cell therapy, we have noticed an overall improvement in his perceptual and cognitive skills including meaningful eye contact, increased attention and concentration, and increased awareness of his surroundings.

One of the major improvements I've seen in Leo is his improved tolerance and attention span. Earlier, he used to just roam around the house aimlessly and not sit in a place for more than a minute longer. He now sits in a single position for almost 1- 2 hrs without getting agitated. His learning abilities have improved beyond recognition. My little son, who was unable to hold a pen earlier, can now write alphabets, numbers and can draw lines with ease. He takes an interest in the homework assigned to him and tries his level best to finish his work with minimal assistance.

His social interaction and communication skills have also shown a drastic improvement. When his father would take him to the playground earlier, he also wound up getting hyper and never interacted with the other children. He now waits patiently for his turn on the swings and attempts to play with the other children. At home, he expresses his needs by pointing correctly to the objects he needs. If he feels any pain, he can point out to the correct body part. Previously, he preferred being aloof and silent. He now enjoys spending his time with us. After meals, he often lingers back in the den with his father playing his games rather than withdrawing in his room. His eating habits have also improved. He now tries all the food items presented to him as opposed to when he insisted to have only pizza, pasta, fish fingers and cheese. He also attempts to help with the house work, like cleaning the dishes, arranging his clothes in his wardrobe and so on. He always accompanies me to the supermarket these days and helps me to fetch the items I want. He goes independently to the aisles and picks out the food items he needs without my assistance.

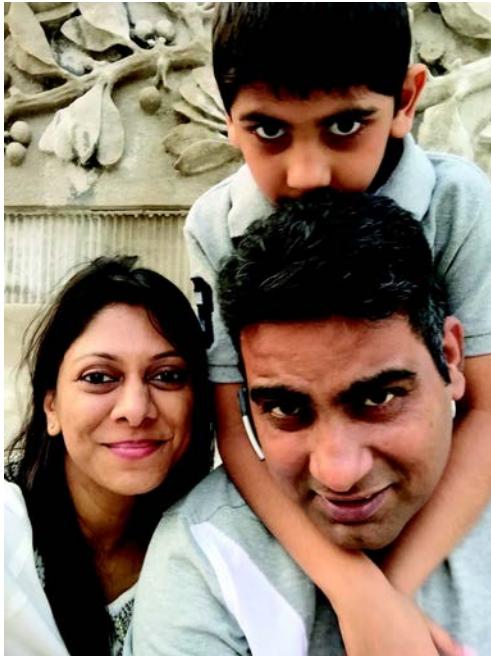
After stem cell therapy, Leo has also shown improvements in the activities of his daily living. He can now dress, bathe, have meals, wear his shoes independently. He has started operating the computer and iPad at home on his own and can play games, watch videos and can type alphabets as well. He has developed interest in various new activities. Leo as a child was always interested in roller skating, but his performance was average due to poor command following and improper balance. Post stem cell therapy, Leo can skate wonderfully well. He can even skate on a single leg as his balance has increased. He likes to practice his skating in presence of other children as well. He's even learning to play my piano at home.

When all we received were negative feedbacks, NeuroGen gave us a hope, that maybe something would work out differently and that is exactly what happened. For us, as parents, this was our only chance of a positive outcome. I am glad we made this decision for our son. Currently, Leo is independent for most of his activities. Of course there are some good days, some bad days. But that does not stray us from our path. We feel confident that one day our son will be living a life of his own, dreaming a dream of his own and we will have the entire NeuroGen Team to thank for!

– *Mrs Marina Vergini*
(Leo's mother)

United States of America

"What is Hope? Hope is wishing for a thing to come true; faith is believing that it will true."



We always hoped our son Ashvik should be able to see the world as we do and should be independent. At NeuroGen Brain and Spine Institute we got this faith.

Ashvik was a week premature and had a birth history of neonatal meningitis and was in NICU for 14 days. Once he was home things seemed fine. He being our first and only child, we didn't know what milestones to look for though the pediatricians informed us that he had delayed developments. At the age of 3 ½ years for a school admission process we had his medicals done and he was diagnosed with CVI (Cortical visual impairment). Our world came to a standstill when we heard this. We went all over the internet finding information on CVI and in India there didn't seem to be much. Our ophthalmologist said we cannot treat him as there was no treatment.

Ashvik was a very smart child, communicated well but used to struggle in his daily activities due to his vision, fine motor and other behavioral issues. He used to get easily frustrated was very hyper active, sensory processing disorder and his attention span was very poor. We were informed by his school to give him some occupational therapy so that his attention span increases.

Since Ashvik spoke well none of the doctors we took him to ever told us that Ashvik might also have Autism but we kept looking into the internet and saw that he does fall into few ASD (Autism spectrum disorder). He would always line up his toys in a

particular order, would not want to share his toys with his friends, would not wait for his turn at a playground, would have lot of meltdowns, and no eye contact. But we as parents often thought it was related to his vision and CVI and didn't think much about Autism. When we got to know about a CVI specialist in USA that's when we decided we should move to USA as we didn't have any treatment option for CVI for Ashvik in India and we were in the belief that Autism has no treatment anywhere in the world.

We have been in USA for more than a year and this year in April 2015 we decided to go to India for a holiday. We learned about NeuroGen through a newspaper cutting that my mother - in - law had saved to show us when we came to India.

When we met Dr Alok Sharma at NeuroGen we started to believe that the issues Ashvik had can be treated.

Ashvik was 7 yrs old when he underwent his first stem cell on 4th May 2015 and it's been only 3 months and we have already seen lot of improvements in him. In all areas of concern (vision, fine motor, attention span, hyperactivity) he has shown improvement, vision being the most prominent. He can now see better as he can point out and identify small objects and also locate objects that are far away. He has begun to have his food on his own using a spoon and with some assistance. He can hold conversations with his peers and likes to play with other kids unlike earlier where he would not like playing with kids. He also has begun to tolerate sound well earlier he would not be able to tolerate sound of a mixer and shut his ears whereas now he can stay in the kitchen even when mixer is running. His attention span has increased and he can stay at one place and concentrate well even at school. He also uses the Ipad independently, earlier he found it difficult and needed assistance. He is very close to getting independent in brushing, cleaning after toilet, bathing and wearing his clothes.

We have seen many positive improvements in Ashvik after the Stem cell therapy and are looking forward to see more and we are very positive and confident that Ashvik will be soon independent and will grow up to be a very good human being.

We are grateful to Dr. Alok Sharma and his team for the Stem cell therapy and the wonderful and memorable experience at NeuroGen Brain and Spine Institute.

– ***Mrs Rekha Tripathi***
(Ashvik's mother)

India

"Ultimately its faith in yourself and hard work that pays off!"

After completing my graduation, I chose teaching as my career path. Teaching not in normal schools, but in special schools meant for specially gifted children. That's where my real interest and passion was.

I've been a special educator since 1991 and have worked very closely with many groups of special kids. Even after I was married, I continued with my profession with the support of my husband and my family. I always discussed the idea of adopting a special child with my family members and

With the birth of my son, Siddharth, it was like God granting me my wishes. In spite of being normal at birth and achieving milestones, I noticed an increased sense of hyperactivity in him as he grew older. At mere 3.5 years, he would throw tantrums and display signs of aggressiveness. Being a special educator, I was well versed with the symptoms he was showing and even before we visited a pediatrician, to get an opinion for his behavior, I knew that Siddharth was an Autistic child. When Siddharth was 5 years old, we visited a psychologist to get him assessed by a professional. She confirmed by prognosis about Siddharth and diagnosed him to be a case of Autism.

Since I had already been dealing with such special children, I was always sure as to how we would be dealing with him. The chief problems exhibited by him were hyperactivity and aggressive, destructive behavior, poor sitting tolerance, poor speech, lack of communication and attention. We started by giving him regular sessions of vocational therapies including psychological counseling, occupational therapy and speech and language therapy. These therapies definitely helped to monitor and stabilize his behavior. However, a consistency in his improvements was something that we were not able to mark out. There were times, when his performance was extremely good and days when he was hyper and aggressive again. But we never gave up on him. We have always encouraged him in whatever activities he does and have tried our level best to provide him with the best available therapies possible.

We have always kept ourselves abreast with all the latest happenings around the globe concerned with autism. In this manner, we came across an article mentioning the role of stem cells for autism. I started my own study into this matter. Coincidentally, during this time period, my parents came across a television show mentioning stem cell therapy for autism. Taking cue, we researched further and came across NeuroGen Brain and Spine Institute. After a visit to the centre and a consultation with Dr Alok Sharma, we were convinced that stem cell therapy could probably help our son. We already knew about stem cell therapy but we were apprehensive about how it can be used in Autism. But after Dr Sharma explained the in depths of the treatment to us, we felt confident towards the approach.

Along with stem cell therapy he was put on an extensive rehabilitation programme. The rehabilitation program was customized in a manner such that it benefits him to the



maximum limit. The aim of rehabilitation program was to improve his motor performance, to channelize his aggression and to help him develop his vocational skills.

Siddharth was already undergoing various therapies when we decided to go for Stem Cell Therapy. However, post Stem Cell Therapy, his performance in therapy sessions has improved. He can now pick up language better as compared to before. Also, his communication skills and understanding is showing a positive growth. Stem cell therapy combined with the correct rehabilitation has helped Siddharth achieve those milestones that he was unable to earlier.

My first years as a special educator and then as a special parent has made me realize, the lack of awareness we have about autism in our society. This along with my son's smiling face has inspired me to start my very own special school where we try to provide therapies of an international standard to Autistic kids from poor socio-economic background. We also try and conduct awareness camps and sensitization programmes in various other schools and campuses. In this way I feel am not only helping my own son but all those other parents and children who are facing similar problems as we are.

Have faith in your child. Have faith in yourself. Have patience. Dealing with a child with autism may not be an easy job, but it is not impossible. Instant miracles or instant success is the not the way. A parent's contribution in terms of their time and their efforts plays a great role. It's ultimately hard work that pays off!

– Mrs. Smita Nair
(Siddharth's Mother)

India

"We are happy that she now helps her mother with the household work"



My daughter Sonia is a 11 year old girl. She had undergone Stem cell therapy at NeuroGen Brain and Spine Institute. Initially, the concept of the treatment was very confusing to me and my wife. We had recently learnt that persons with autism could be treated with Stem cell therapy. We were also scared to try something new and unconventional. However, we decided to approach the staff at Neurogen. The treatment was explained to us by Dr. Alok Sharma and we were satisfied that there were no side effects, nor any risks.

Sonia has improved in her eye contact, listening skills and her observational skills, though her speech has not developed. Her gross motor skills have improved. For example, she can do grooming activities, brushing her teeth, bathing herself and wearing clothes. Also, her fine motor skills have improved due to which she can hold pen, pencil, chalk and brush and attempt writing letters, numbers and drawing. We are presently working on the basic concepts with her teachers. She can distinguish a few colors and identify the alphabets and numbers. Though she is having some behavioral issues, her understanding power has improved as she can follow our commands. Her hyperactivity has also decreased to great extent. We were happy that she now helps her mother in household work. Dr. Hemangi Sane's motivational workshop conducted as part of the treatment at NeuroGen was really good and helpful.

We thank the Neurogen team for the counseling they have given and the help they provided. We had a pleasant stay at Neurogen during the course of my daughter's treatment.

— **MR. Rajesh Randhir**
(Father of Miss Sonia Randhir)

India



Vaibhav is my eight year old son. He was born as a normal healthy child. As he grew up, my husband and I started to notice that something was amiss. He showed a delay in physical and social development. His slowed development, lack of any speech and poor responses at the age of two years concerned us. We took him to a pediatrician; and after a few tests and some examinations, he was diagnosed with autism. This was difficult to understand for me and my family. He was started on occupational therapy, physiotherapy and speech therapy as per the doctor's recommendations. By the age of three he started to stand and he was four and a half years old when he began to walk.

We were worried about his future, schooling and how he would cope in a new environment because he did not interact with others, mostly remained aloof and could speak only few sounds (monosyllables). We initially put him in a special school but going there, his behavioral problems only increased. We shifted him to a regular school where the teachers specifically managed his problem behaviors. He was responding well to school but still several problems hindered his performance and participation. He had poor eye contact, repetitive behaviors, hyperactivity and poor attention and concentration. He was unable to relate to, interact with or play with other children of his age. He was very fearful of climbing stairs. We were unable to train him for daily activities like brushing, eating, toileting, etc. We were looking for some better treatment options when we learnt about stem cell therapy at NeuroGen Brain and Spine Institute.

We had several doubts about the treatment procedure, effectiveness, safety, etc; all of which were cleared and explained to us in detail by the doctors and therapists. A few tests were conducted and the procedure was done for Vaibhav in July, 2012. Advice on management at home and further therapies to be continued after stem cell therapy were given. Therapy and recommendations from the psychologist, occupational therapist, speech therapist and dietician were followed. Within three months of having taken stem cell therapy we began to notice some improvements in him.

Eye contact improved noticeably, especially to people whom he recognized. His attention span got better; previously he was never able to attend to a writing task. Previously

while coloring within a circle, he wouldn't be conscious of the borders but now he developed the awareness and started to color inside the circle. His color matching skills improved. Boredom would make him restless and wander up and down but slowly he learnt to engage himself with an activity. Drooling stopped completely and tongue movements got better. Now he chews food on the left side as well, which was previously difficult. His imitation of sounds is better with the speech therapist. His recognition and awareness about his surroundings has increased. His fears had reduced; he was able to step onto the pavement while crossing the road. Even the fear of climbing stairs almost completely disappeared. His cycling and skating abilities were better as compared to before (i.e.) his stamina and balance had improved. Previously, while bathing he would not like to hold a scrub and a soap but slowly he became tolerant to them and even assisted in bathing. His grip has become better; previously the pen or pencil would slip from his hand. Command following has improved; previously he would follow commands like "sit down", "get up", "go back", etc. Now he follows even slightly more complex ones like "bring me the water jug", "pick up the sandal", "take your sandal outside and wear it". Previously commands needed to be repeated a couple of times but now he follows it up immediately. Vaibhav started to interact with other children. He began sitting in a group and would even tickle other children. We have noticed some development of emotions like happiness, respect, etc. which were not present before. He is even aware about having soiled his pants. A few steps of toileting like undoing his pants in the toilet have been learnt by him.

Six months after therapy many more positive changes occurred. His understanding of concepts of addition and multiplication improved. He was able to understand and perform exercises related to grammar. Vocabulary and imitation skills improved. He was able to recognize animals, birds, etc. Body tone improved and posture got better. Sitting tolerance for an activity increased to half an hour at a stretch. Earlier I had to supervise his activities even at home. Now I can let him be unsupervised, even at the playground. The prompts required during Prompts while eating, brushing, dressing-undressing, etc. reduced. We were also told that changes were recorded on the PET-CT scan of the brain.

All these positive improvements gave us confidence. We are hopeful and know that Vaibhav will make his way through. We are even planning to get a second round of stem cell therapy for him as we believe that there is more scope for improvement with this intervention. My husband and I are grateful to the entire team at NeuroGen for their help and support.

— **Mrs. Salunke**
(*Vaibhav's mother*)

42. Temple Grandin.... The Autistic Legend



Temple Grandin, an American doctor of animal science and professor at Colorado State University was born on August 29, 1947. In 2010, she was listed in the Time 100 as one of the 100 most influential people in the world. She is well known as an autism activist, bestselling author and consultant to the livestock industry on animal behavior. With a diagnosis like autism she always knew she was different from the others. Today, her exceptional contributions make the world of autism more fathomable to us.

Her life story is definitely something to draw inspiration from. Born to Richard Grandin and Eustacia Cutler in Boston, Massachusetts; Temple was the first of four children. She was initially labeled "brain damaged" or "psychotic" until she was diagnosed with autism at the age of 5 years. At that early age she was placed in a structured nursery school with what she considers to have been good teachers. She says "I was lucky to be surrounded by a supportive team of adults from almost the very beginning." Her typical day included speech therapy, three Miss Manners meals (where table manners were strictly insisted on), and hours of turn-taking games with her nanny. Structure was an important characteristic of her day. For one hour every day, she was permitted to revert to repetitive, autistic behavior.

Grandin suffered from delayed speech development, as she began talking at the age of four. However, Grandin has said that middle and high school were the most difficult times of her life. She was the "nerdy kid" whom everyone made fun of. She was even called by names like "tape recorder" as she often repeated things over and over again. She says that rules and disciplining helped her function better at home and in school.

After graduating from Hampshire Country School, a boarding school for gifted children in Rindge, New Hampshire in 1966, Grandin went on to earn her bachelor's degree in psychology from Franklin Pierce College in 1970, a master's degree in animal science from Arizona State University in 1975, and a doctoral degree in animal science from the University of Illinois at Urbana-Champaign, in 1989. It was during her study of animals that she devised the "hug-box". It was used by her to calm herself with pressure whenever she was anxious, angry or upset. Grandin received an honorary doctorate degree from the Ontario Veterinary College, University of Guelph in Guelph, Ontario, Canada at the 2012 Winter Convocation, where she was the keynote speaker. On May 16, 2010, Grandin also received an honorary Doctorate of Humane Letters from Duke University.

Grandin is a leader of both the animal welfare and autism advocacy movements. Being autistic, she knew the anxiety of feeling threatened by everything in her surroundings, and of being dismissed and feared. This was her connect with animals. It motivates her work in humane livestock handling processes. Her business website promotes improvement of standards in slaughter plants and livestock farms.

Grandin became famous after being described by Oliver Sacks in the title narrative of his book *An Anthropologist on Mars* (1995); the title is derived from Grandin's description of how she feels around neurotypical people. She first spoke in public about autism in the mid-1980s, at the request of Ruth C. Sullivan, one of the founders of the Autism Society of America. She was also the subject of the 2010 award winning biopic film titled "Temple Grandin" by Mick Jackson. She has been featured in several TV shows and documentaries since.

Based on personal experience, Grandin promotes early intervention to address autism, and well trained supportive teachers who are capable of channeling a child's abilities and directing the fixations of a child with autism towards fruitful directions. Her hypersensitivity to noise and other sensory stimuli have posed several hindrances. She always wears comfortable clothes to counteract her sensory integration dysfunction and has structured her lifestyle to avoid sensory overload. She regularly takes anti-depressants, but no longer uses the squeeze-box (hug machine). The squeeze-box is a device which she invented at the age of 18 as a form of stress and anxiety relief therapy. Primarily, she is a visual thinker and images are her first language. Temple attributes her success as a humane livestock facility designer to her ability to memorize visually and recall detail. Despite her inconsistent eye contact she conducts regular workshops and presentations on autism and its awareness in front of large audiences.

Her insight into the minds and behaviors of cattle has made her vigilant and appreciative of the changes in details to which animals are particularly sensitive. She was intelligently, pragmatically and creatively use her visualization skills to design thoughtful and

humane animal-handling equipment. In 2009, she was named a fellow of the American Society of Agricultural and Biological Engineers. Besides her work in animal science and welfare and autism rights, her interests include horse riding, science fiction, movies and biochemistry.

The norms of relationships cannot be comprehended by Grandin in a way similar to us. Grandin says that "the part of other people that has emotional relationships is not part of me," and she is neither married nor has had any children. In her autobiographical works she has identified how autism affected every aspect of her life. Having said that, she also has expressed that she would not support a cure of the entirety of the autism spectrum as it is a partial proponent of neurodiversity.

SUMMARY :

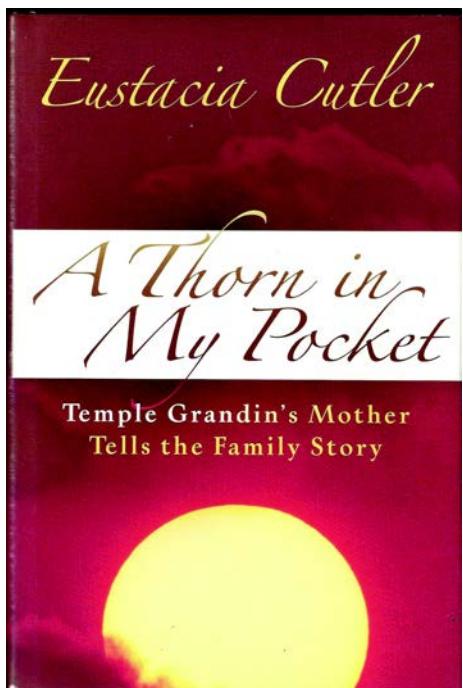
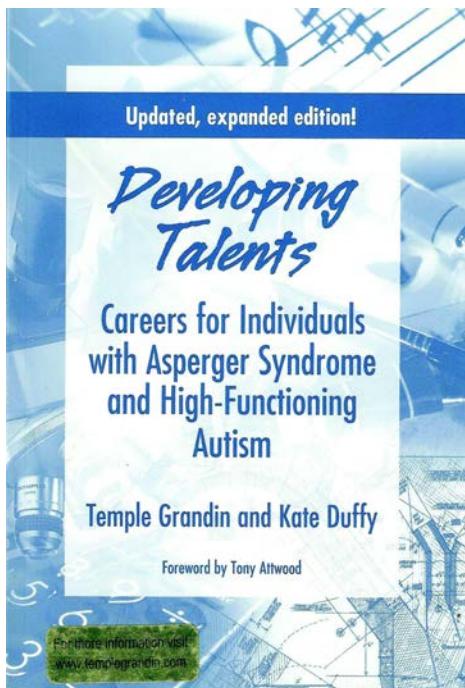
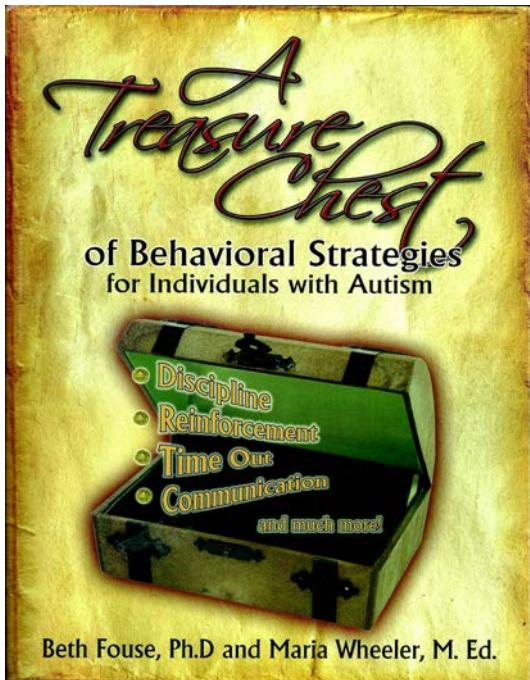
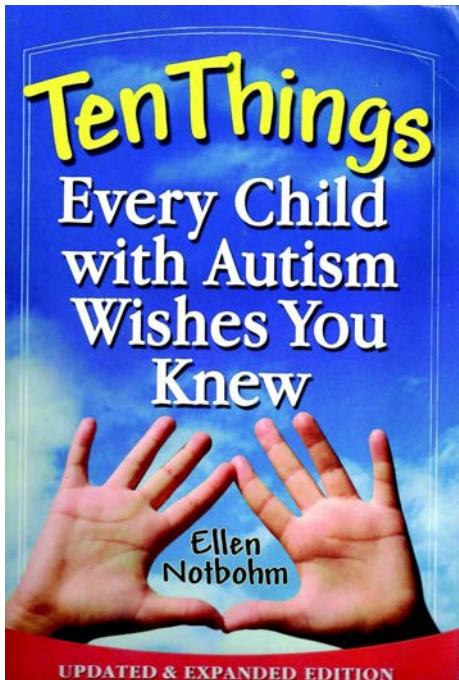
While there is sufficient focus on the symptoms, problems and impairments seen in children with autism, we believe that it's important for you to identify their positives. The special traits of those with autism are the highlights of their personality and identify in our society. Identifying and nurturing them will make their existence more meaningful, provide a base for a productive future and will keep you motivated throughout the journey.

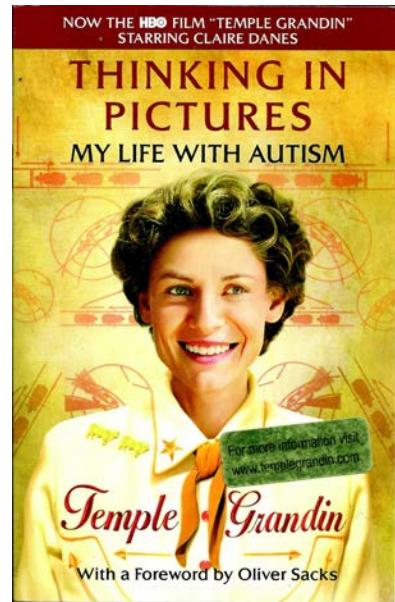
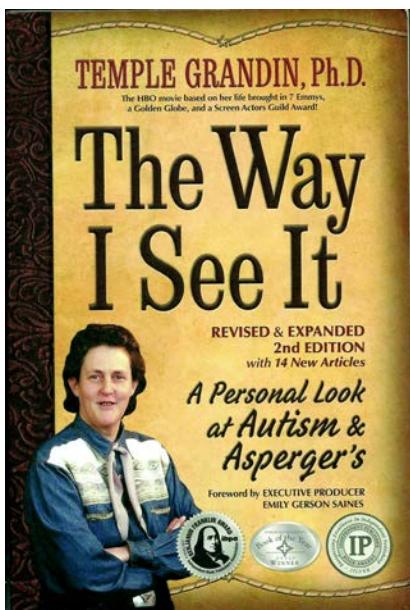
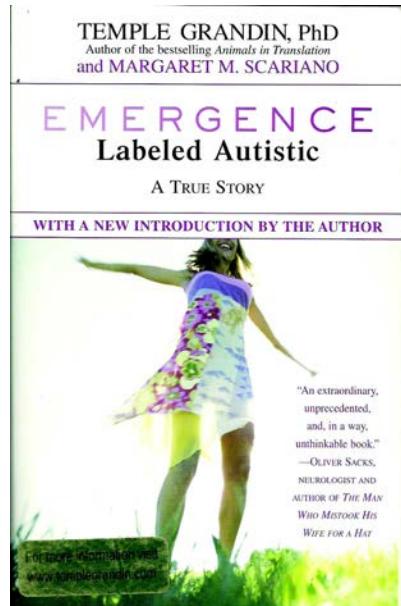
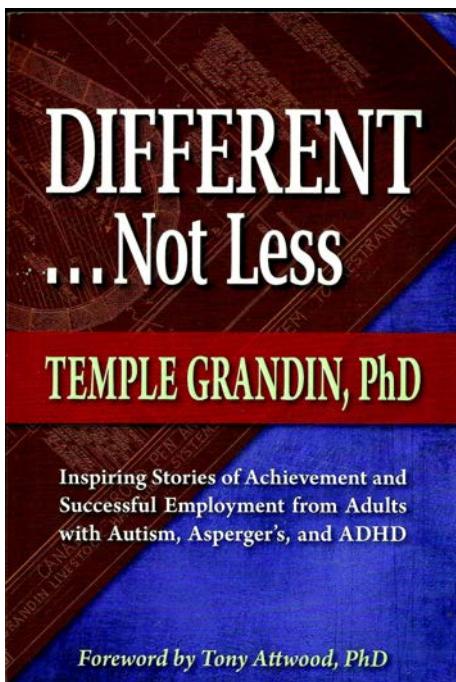


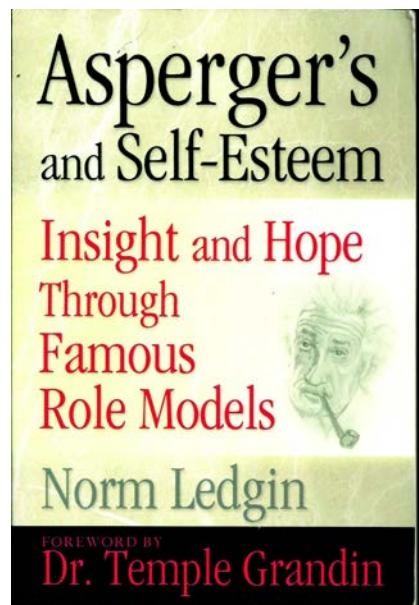
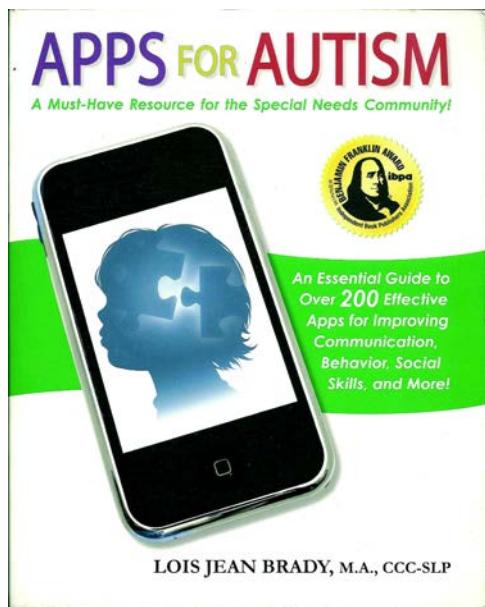
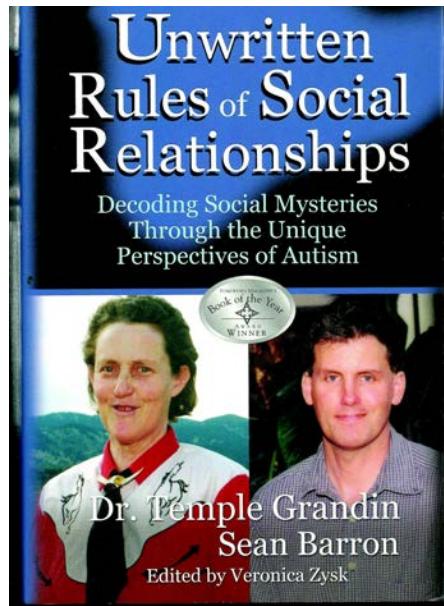
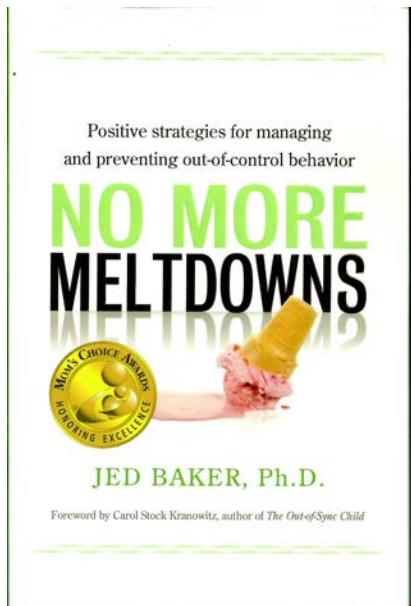
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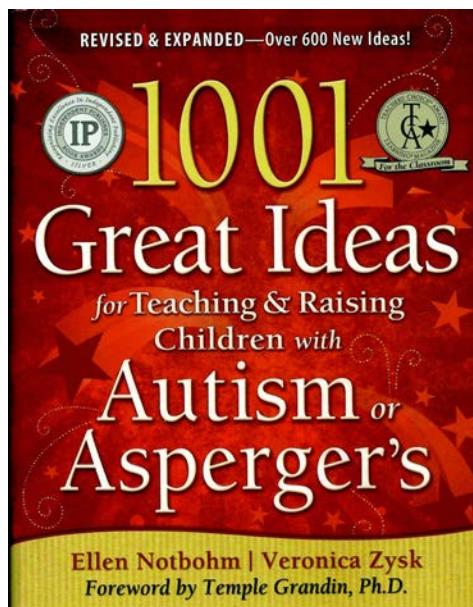
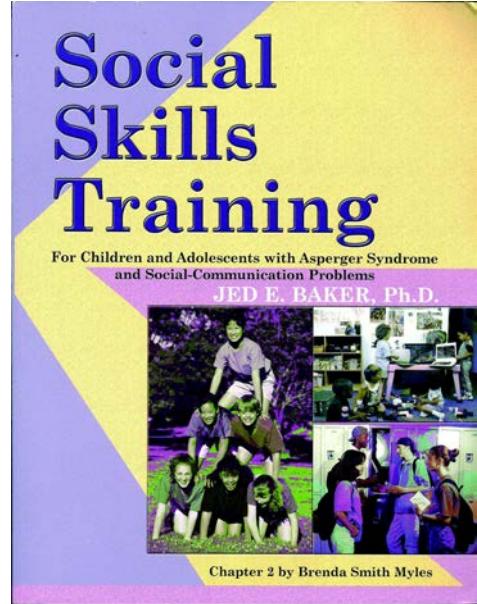
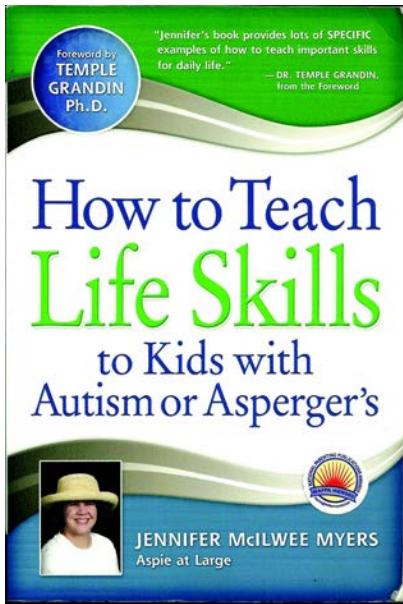
Just the Right Information

43. Books for further reading











APPENDIX

Scientific Publications on Stem Cell Therapy in Autism by the Authors

A) AUTISM:

1. Alok Sharma, Nandini Gokulchandran, Hemangi Sane, Anjana Nagrajan, Amruta Paranjape, Pooja Kulkarni, Akshata Shetty, Priti Mishra, Mrudula Kali, Hema Biju, Prerna Badhe. Autologous bone marrow mononuclear cell therapy for autism - an open label proof of concept study. *Stem cell international*. 2013 (2013), Article ID 623875, 13 pages.
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Scientific Publications on Stem Cell Therapy in Other Neurological Disorders by the Authors

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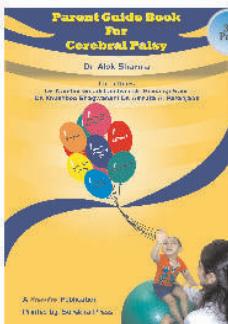
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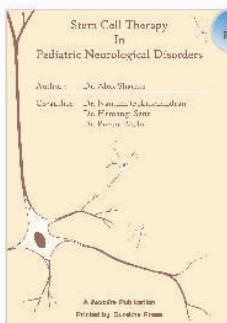


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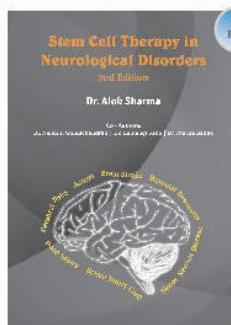
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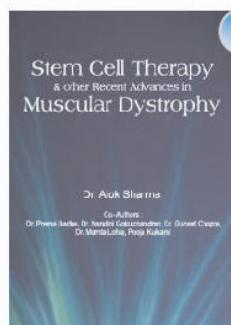
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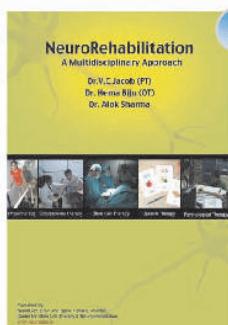
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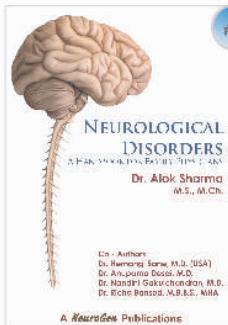
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