

# Autistic children jostle for own space in a disabling environment

Wanting to compete with the world, the children with Autism Spectrum Disorder (ASD) are showing that it's not their disability but the disabling environment which restricts their journey to self-actualisation. Their words are repetitive and restricted to few actions, writes **NIBEDITA SEN**

*"Know me for my abilities, not my disability"*  
- Robert M Hensel

I am passionate about computers", says Eshan Kamat, who spends his idle hours in research and reading encyclopedia. "I got a distinction in 10th and 72 per cent in 12th Board exams," says a gleeful 22-year-old Eshan.

But behind this success lies the many sleepless nights spent by Eshan's mother Maya Kamat. Being a mother of an autistic child is not easy. On one hand she

of being mother of an autistic child in a book. "I wrote a book to create awareness. I wanted to spread the word amongst each abled person. I am unable to market it as I have a job besides dealing with the challenge of Autism. It is not a disease, it does not need to be cured," Maya Kamat says.

Every 1 in 42 boys and 1 in 189 girls are affected by autism in Goa. There is no "cure" for

trained. Some are good in academics and some in vocation," Kalokhe says.

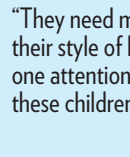
While there is no cure as such, but awareness can help in early detection and intervention with various therapies.

"We can only help by creating awareness. The therapist gives necessary therapy for the child's progress. The skill development is done through painting, dancing, singing etc so that they can do some jobs like stamping, as-



"Autism needs to be understood and accepted so that those affected can reach their full potential."

Maya Kamat, mother of Autistic son



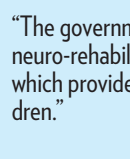
"They need multi-professional support, as their style of learning is different. One-to-one attention is required in order to observe these children."

Sarada Kumar, special educator



"We have started a DEd course for teachers at pre-primary and primary level to serve in special schools, integrated inclusive setups to help autistic kids."

Raj Vaidya, Secretary of Lokvishwas Pratisthan



"The government of Goa has started the neuro-rehabilitation centre next to GMC, which provides services for Autistic children."

Dr Amit Dias, Chairperson of Sangath

## Types of interventions for ASD

### Behaviour and Communication Approaches

- Applied behaviour analysis (ABA).
- Encourages positive behaviours
- Discourages negative behaviours
- Improves a variety of skills.
- The child's progress is tracked and measured.

### Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH)

- TEACCH uses visual cues to teach skills. For example, picture cards can help teach a child how to get dressed by breaking information down into small steps

### Occupational Therapy

- Occupational therapy teaches skills that help the person live as independently as possible.
- Skills might include dressing, eating, bathing, and relating to people.

### Sensory Integration Therapy

- Helps deal with sensory information, like sight, sound, and smell.
- Could help a child who bothered by certain sounds or does not like to be touched.

### Speech Therapy

- Helps to improve the person's communication skills.
- Some people are able to learn verbal communication skills.
- For others, using gestures or picture boards is more realistic.

### The Picture Exchange Communication System (PECS)

- PECS uses picture symbols to teach communication skills.
- The person is taught to use picture symbols to ask and answer questions
- Have a conversation.

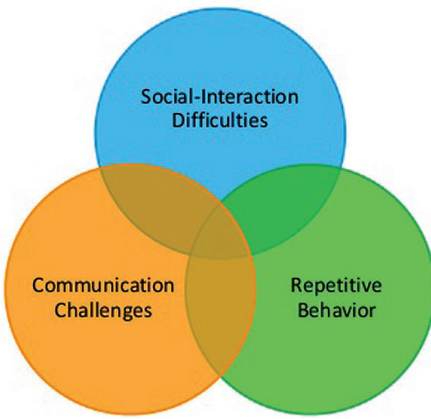
### Medication

- There are no medications that can cure ASD or even treat the main symptoms.
- But there are medications that can help some people with related symptoms.
- For example, medication might help manage high energy levels, inability to focus, depression, or seizures.

(Source: Centre for Disease Control and Prevention (CDC, USA))

## What are the Symptoms?

3 Core Symptom Interactions



Early Signs of Autism	
Before 12 Months	After 12 Months
No joyful expressions	No words (16 months)
No sharing of sounds or facial expressions	No meaningful two-word phrases (24 months)
No babbling	Lack of social interaction
No gestures such as waving or pointing	Prevalence of behavioral issues

## WORLD AUTISM DAY

Bambolim which provides services for children Autism. Sangath has also been associated with the cause since its inception for the last 20 years.

According to Secretary of Lokvishwas Pratisthan, Raj Vaidya, the organisation has

started a DEd course to prepare teachers at pre-primary and primary level to serve in special schools, integrated inclusive setups to help autistic kids.

"Our aim is to build adequate knowledge in various aspects of disability, its impact and management, key aspects of education like goals, functions, technology and emerging trends," says Vaidya.

This will help develop skills in personal, professional and social competencies required in teachers, developments and adaptations of instructional material, classroom management techniques and individual and group parents interactions.

"They need multi-professional support, as their style of learning is different.

One to one attention is required in order to observe these children," says Sarada Kumar, a special educator since last 18 years.

(see interview)

I am Beautiful  
Not Broken  
Different  
Not Defective  
Challenged  
Not Challenging  
I am Autism  
Watch Me Fly

Always  
Unique  
Totally  
Interesting  
Sometimes  
Mysterious



Eshan Kamat (2nd L) with former Governor of Goa Bharat Vir Wanchoo (2nd R) holding Eshan's painting. Also seen are Eshan's parents.

had to cope with her son's disability and enable him to compete with the world while on the other hand was the challenge to cope with the insensitive society.

"I had to be positive and multi task all new duties that came with parenting autism. I was a mother with extra duties. I played a mother, a teacher, in house therapist. I had to do advocacy for my boy. I had to add up positive energy, create awareness, make the world understand that there is a great human being besides the label of Autism," she says.

In her hour of crisis, it was her parents, her maid and office colleagues who helped her to cope with the situation. She also went on to pen her experiences

autism, but the mental health specialists now have a better idea of what could cause autism and how to treat it. Most cases of autism seem to be caused by a combination of genetic predispositions and environmental factors which may influence early brain development.

Secretary of Disha Charitable Trust, Sandhya Kalokhe informs that there are 21 intervention centres in Goa.

"We cater students from 5 to 35 years of age. We can find out the extent of Autism in a child by measuring the Intelligence Quotient (IQ). IQ score above 50 to 69 is mild, 35 to 50 moderate, 25 to 35 is severe and below 20 is profound. Mild and moderate cases can be

sembling something, cleaning, packaging or the role of a liftman," she says. Through its efforts, Disha has been able to place 10 students with jobs.

Children with special need and families seeking help in Goa are also supported by NGOs like Sethu, Sangath, Lokvishwas Pratisthan and DRAG (Disability Rights Association of Goa), Jyot Special Care, Peace Heaven and Daddy's Home, which are building bridges of hope for precious children, giving them a chance to live their dreams for a joyful future.

Chairperson of Sangath, Dr Amit Dias says, "The government of Goa has started the neuro-rehabilitation centre next to GMC,

## 'Autistic kids need multi-professional support'

Special educator in Disha School for Special Children, Panaji Sarada Kumar speaks to **NIBEDITA SEN** about ASD. Here are excerpts.

**Q. Which are the areas affected by Autism?**

**Ans.** Mainly Autism affects three areas - social communication, speech ability and thinking.

**Q. What are the general symptoms that an Autistic child has?**

**Ans.** They do not keep proper eye contact. They also have sensory disorder. They may not hold the things in hand, they just pick up and draw.

**Q. What kind of attention do these kids need?**

**Ans.** They need multi-professional support, as their style of learning is different. One-to-one attention is required in order to observe these children. By prompting they learn faster, so that their actions can be well defined.

**Q. What is the challenge Autistic adults face?**

**Ans.** They face different problems from childhood. Once these chil-

dren cross 18, their hyperactivity reduce, most of the problems tend to ease out.

**Q. What should be the approach of parents towards these children?**

**Ans:** These children are special and they should be treated specially. So the parents must accept this first. Parents should also go through continuous training to treat them better.

**Q. What is the connection of nutrition with Autism?**

**Ans:** Most of the Autistic children suffer from deficiency of proper nutrition. Due to lack of zinc and magnesium the sensory problems occur. Lot of Autistic children keep rubbing their fingers. This is a type of sensory disorder. So the right amount of nutrition should be given to them. There are other problems too. They cannot wear wet clothes. Irritation causes due to sensory problems.

Lokvishwas Pratisthan has started a DEd course to prepare teachers at pre-primary and primary level to serve in special schools, integrated inclusive setups to help autistic kids. Following is the course outline:

### Theory:

- Introduction to disabilities (intellectual disability, autism, hearing impairment, visual impairment, multiple disabilities)
- Inclusive education for the children with disabilities
- Legal/policies concerned with children and disabilities
- Autism spectrum disorders, nature, needs and etiology
- Assessment and development of independent living skills (self help skills, functional skills)
- Therapeutics and intervention (speech therapy, occupational therapy, medical intervention and alternative therapies, counselling and cognitive behaviours management)
- Vocational and adulthood (adult living, rehabilitation and habilitation)

### Practical:

- Individual Education Program (3 months per year)
- Individual vocational transition program (3 months per year)
- Behaviours management therapy
- Occupational Therapy
- Speech Therapy
- Group Teaching

### Eligibility:

- Completion of 10 +2/ Equivalent with minimum 50% marks
- For SC/ST category minimum 45%
- Additional Qualification - Graduate and above

### Duration of the course:

- 2 years

### Objective:

- Develop the understanding of characteristics and etiology of Autism and associated conditions.
- Be familiar with process of screening and diagnosis of ASD
- Be acquainted with the stages of child growth and developments along with psychology of learning
- Plan and implement educational programs selecting teaching suitable for children with ASD
- Integrate the prescribed therapeutic programs within classroom
- Understand the needs of family and promote integration of person with ASD within family and community

### Job potential:

One can set up their own NGOs or they can work in following:

- Special School
- Resource school
- Clinics
- Hospitals
- Health agencies
- Early intervention program
- Residential facilities

### First batch pass out date:

- July 2017.