

# Awareness about Autism among Parents

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**Abstract:** Education is the key to awareness. Keeping in mind the importance of early identification, the researcher identified a sample (n=200) in Ernakulam, Kerala State, that are unaware about Autism Spectrum Disorder (ASD). The methodology included preparation of pictorial slides for the learning package, a self-designed questionnaire, to assess the awareness level about autism, before and after the educational programme. A booklet and pamphlet about ASD was also prepared. The results were subjected to percentage analysis

**Keywords:** Awareness, Autism, Early Identification, Parents, Individualized Educational program (IEP)

## 1. Introduction

Childhood is a demanding and challenging period for all parents and when a child has problem, the demands and challenges are magnified. When the problem is autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope (Glass, 2001).

The word autism comes from two Greek words "aut" (meaning self) and "ism" (meaning state) and is used to define a person who is unusually absorbed in himself. Children with Autism Spectrum Disorder (often called ASD) have in one form or another, difficulties in developing and retaining relationship with others.

According to Wagner (2006) Autism Spectrum Disorder (ASD) range from the severe disorder labelled Pervasive Developmental Disorder to the milder disorder called Asperger's Syndrome.

According to Santrock 2011, Autism Spectrum Disorder is a developmental disorder that involves a wide range of problematic behaviour including deficits in language and perceptual and motor development, defective reality testing, and an inability to function in social situation.

"Autism is a brain disorder that typically affects a child's ability to communicate, or relationship with others and responds appropriately to the environment. Some children with autism are relatively high functioning, with speech and intelligence intact, others are mentally retarded mute, or have serious language delays (Baron et. al, 2011)

## 2. Causes of Autism

Little is known about what causes autism, but some theories exist. Autism research reports suggest that autism is the result of a deregulated immune system in children that is triggered by a virus or genetic disposition. Autism may be caused by intrauterine, prenatal or neonatal stress or trauma (Walden, 2000).

Cowley (2000) reported that the weakened measles virus

used in the MMR vaccine had infected the children's intestine, disrupting the normal process by which nutrients are absorbed by the blood and brain and harmful substances are denied entry.

## 3. Behaviour and Cognitive Effects in an Individual with Autism

Whatever the causes may be, the effects of autism on the cognitive and behavioural process of children are devastating. Autism is a severe disruption of the normal developmental processes that occur in the first two years of life.

The most important thing to realize is that autistic behaviours do not happen in a vacuum. They happen in a family system. Common behavioural characteristics of autism vary widely from child to child, but some are prevalent in most autistic children. Obsessive behaviours as not stepping on tracks in the sidewalk, repetitive flapping of the arms and hands are present. Other characteristics of autism include poor and non-existent toilet skills, refusing food, aimless wandering with no fear of getting lost, climbing on dangerous and inappropriate objects and little or no communication. Echolalia, the repeating of sounds and words, is quite common. They may excel on the computer, yet cannot ask for a glass of milk and in some cases cannot chew food. There is no comprehension of hygiene or respect for others or their property. Bizarre body movements and stiffening of their body are often present (Coggins, 1988).

## 4. IEP (Individualized Education Program)

An Individualized Education Program (IEP) is a written document prepared for a named student which specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources and supports necessary to achieve those goals (Murray, 2006).

## 5. Alarming Statistics

Autism is now a national emergency. The number of children diagnosed with autism or related disorders have grown to an

alarming rate. In the 1970s and 1980s, about one out of every 2,000 children had autism. Now experts estimate that every 2-6 children out of every 1000 have autism.

Today, the CDC (Centre for Disease Control and prevention) estimates that one in 150, 8 year olds in the U.S. has an autism spectrum disorder, or ASD. According to Autism Developmental Disabilities Monitoring (ADDM) network:

- 1) About 1 in 68 children has been identified with Autism Spectrum Disorder (ASD).
- 2) Boys (1 in 42) are four times more likely to have autism than girls (1 in 189).
- 3) About 40% of children with autism do not speak. About 25% –30% of children with autism have some words at 12 to 18 months of age and then lose them. Others might speak, but not until later in childhood.
- 4) About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities such as intellectual disabilities, cerebral palsy (CP), and autism.

The present scenario in India is also similar. The prevalence rate of autism in India is 1 in 250 (figure may vary as many cases are not diagnosed) and currently 10 million are suffering in India. The govt. of India only recognized the disorder in 2001. Till 1980s, there were reports that autism didn't exist in India (Times of India, 2013).

## 6. Relevance of the Study

Identification of children at risk for ASD at 12 months could provide a substantial number of children and their families with access to intervention services months and years before they would otherwise receive a traditional diagnosis.

Years ago, parents were often told to institutionalize and forget about their child on ASD spectrum. Today information about ASD can be found all around us- on television radio, website and internet searches (NAS, 2011). Despite widespread access to information, few young parents and adults are sometimes left uncertain about early identification of speech and language delays, motor developmental skills associated with ASD and IEP (Individualized Education Program) services which recommend special educator teacher, therapist, and paediatrician to help them create a consistent plan for behavioural modification along with education of children with ASD.

Keeping in mind the importance of early identification the researcher found it imperative to identify a sample that are unaware about autism spectrum disorder and supplement them with information available in this area. Education is the key to awareness and hence a study titled “**Awareness about autism among parents**” was launched with the following aim and objectives:

### Aim

To create an awareness about Autism Spectrum Disorder (ASD) among parents.

## 7. General objectives

- 1) To gain an exposure to the method of designing questionnaire, gathering and assimilating data and critically analysing it.
- 2) To learn the basic art of writing a research dissertation and referencing pertaining to the selected topic.
- 3) To observe the art of collecting review pertaining to autism reference.

## 8. Specific objectives

- 1) To assess the awareness about autism among the sample with the help of a self- prepared questionnaire.
- 2) To educate the parents about developmental delays for early identification, and the availability of Individualized educational plan for autistic children through an awareness program.
- 3) To prepare a pamphlet and booklet which provides a glimpse about autism and its management.

## 9. Methodology

“Methodology is the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose” (Kothari, 2001). The methodology adopted for conducting the present study titled “Awareness about autism among parents” is given under the following sub headings.

- 2.1 Selection of tool
- 2.2 Conduct of the study
- 2.3 Analysis of data

### 2.1 Selection of Tool

Step 1: Formulation of Questionnaire

Questionnaire is the heart of the survey operation. Closed structured questionnaire in which definite, concrete and predetermined questions was prepared by the investigator to conduct the research (Kothari, 2014). The questionnaire schedule comprised of questions to obtain information about the knowledge on autism developmental delays associated with autism and IEP (Individualized Education Program). With the intention to collect relevant information on autism spectrum disorder, the researcher reviewed books, journals, newspapers, e-books for obtaining the relevant information pertaining to the topic to prepare the questionnaire.

Step 2: Development of an e-learning package

A picture can convey the content of the awareness programme easily than lectures. The investigator prepared pictorial slides for the learning package.

Step 3: Development of a Pamphlet

Pamphlet was distributed to the parents as a take home information material about autism. The contents included :

- What is autism
- Causes of autism
- How can we diagnose autism?
- How can we treat autism?

Step 4: Development of a Booklet  
 A Booklet was prepared in English.

### 2.2 Conduct of the study

The investigator with the help of the school authorities informed the parents about the awareness programme. When the parents gathered, the awareness programme was conducted in three phases as follows:

Phase 1: Pre test questionnaire: - The prepared questionnaire was given to the sample in order to assess their existing knowledge about autism. The questionnaire consisted of 54 structured questions in English.

Phase 2: Awareness program: - The awareness program was conducted with the help of e-learning package consisting of slides which included the signs of autism, causes and how it can be managed.

Phase 3: Post test questionnaire: - After the awareness program, questionnaire was given to all of them to assess their knowledge they have gained from the educational programme.

### 2.3 Analysis of data

The data collected was subjected to percentage analysis. The results obtained along with discussion are presented in chapter 3.

## 10. Results and Discussion

The results of the study, "Awareness about autism among parents" are discussed under the following heads:

### 3.1 Awareness about autism

- 3.1.1 Awareness about Social interaction difficulties
- 3.1.2 Awareness about Speech and language skills delay
- 3.1.3 Awareness about Motor developmental skills delay

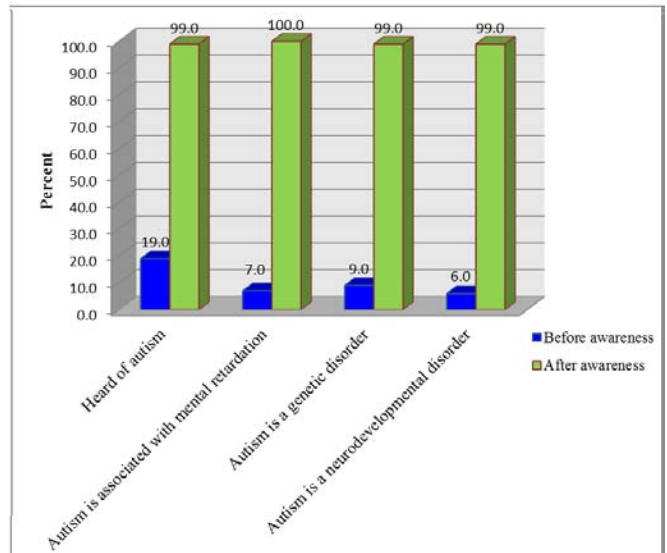
### 3.2 Awareness about Individualized Educational Programme (IEP)

#### 3.2.1 Awareness about autism

Autism is an epidemic and needs to be understood by all. The following table generates the knowledge of the respondents about the basic aspects associated with autism.

**Table 1: Awareness about autism among Parents**

Aspects	Responses ( n= 200 %)	
	Before Awareness Programme	After Awareness Programme
Heard of autism	19	99
Autism is associated with mental retardation	7	100
Autism is a genetic disorder	9	99
Autism is a neuro developmental disorder	6	99



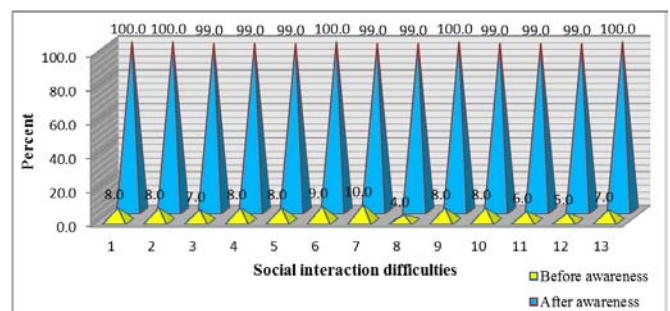
**Figure 1: Awareness about autism**

#### 3.2.2 Awareness about Social Interaction Difficulties

Children with ASD demonstrate qualitative differences in social interaction and often have difficulty establishing relationships. They may have limited social interactions or a rigid way of interacting with others. Their difficulties with social communication should not be seen as lack of interest or unwillingness to interact with others. The following table depicts the awareness about social interaction difficulties that children with ASD are likely to face among the selected sample before and after awareness program

**Table 2: Awareness about social interaction difficulties**

Aspects	Responses ( n= 200 %)	
	Before Awareness Programme	After Awareness Programme
Poor Eye Contact	8	100
Excess fear of noise	8	100
Lack of social smile	7	99
Inappropriate peer relationship	8	99
Lack of interest in surroundings	8	99
Banging his/her head	9	100
Abnormal expression of joy	10	99
Inappropriate emotional	4	99
Lack of ability to imitate	8	100
Inappropriate anxiety	8	99
Doesn't like to be touched	6	99
Ignores pain	5	99
Hates crowd	7	100



**Figure 2: Awareness about social interaction difficulties**

Social interaction difficulties:

1. Poor eye contact
2. Excessive fear of noise
3. Lack of social smile
4. Inappropriate peer relationship
5. Lack of interest in surroundings
6. Banging his/her head
7. Abnormal expression of joy
8. Inappropriate emotional responses
9. Lack of ability to imitate
10. Inappropriate anxiety
11. Doesn't like to be touched
12. Ignores pain
13. Hates crowd

Most autistic children will not make direct eye contact, even when they are engaged in an activity or conversation with another person (Coleman, 1989). It is evident that it is one of the social interaction difficulties that ASD children face that the respondents have comprehended after the awareness program.

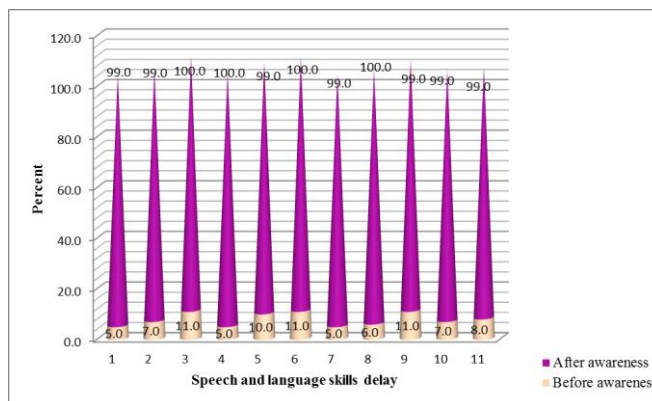
### 3.2.3 Awareness about Speech and language skills delay

Children with ASD may not develop traditional oral language, but most do develop some form of communication. People involved with the student need a thorough knowledge of the student's form of expression and may need to adjust their expectations for communication. For students with limited oral expression, teachers and families should accept limited verbal attempts and non verbal behavior as communicative (Hodgdon, 1995). The following table depicts the awareness level about speech and language skills delay among children with ASD among the chosen sample.

**Table 3:** Awareness about speech and language skills display

Aspects	Responses (n= 200 %)	
	Before Awareness Programme	After Awareness Programme
Loss of acquired speech	5	99
Produce unusual noises	7	99
Voice louder than required	11	100
Frequent gibberish language	5	100
Difficulty in understanding basic things	10	99
Pulls parent around when wants something	11	100
Difficulty expressing needs	5	99
Repeat heard words	6	100
Cannot sustain conversation	11	99
Monotonous speech	7	99
Repetitive language	8	99

This in the line with the studies by Prizant, & Duchan, (1981) that some students with ASD demonstrate echolalia, the literal repetition of words or phrases from language of other people. Immediate echolalia can be used as a teaching tool. Delayed echolalia utterances may have no obvious meaning for the listener. Students with ASD frequently repeat television commercials word for word. Sometimes families and teachers never figure out a logical connection for delayed echolalia utterances.



**Figure 3:** Awareness about speech and language skills delay

Speech and language skills delay:

1. Loss of acquired speech
2. Produce unusual noise
3. Voice louder than required
4. Frequent gibberish language
5. Difficulty in understanding basic things
6. Pulls parent around when wants something
7. Difficulty expressing needs
8. Repeat heard words
9. Cannot sustain conversation
10. Monotonous speech
11. Repetitive language

### 3.2.4 Awareness about Motor developmental skills delay

The delayed motor maturation is the inability to balance, walk and use the hands and fingers, and hand-eye co-ordination at appropriate age. Trouble putting puzzles or toys together, inability to walk, sit, stand or crawl at the appropriate age, extreme reactions to pain, being touched, or textures are typical delayed motor development skills exhibited in an autistic child (Williams 1995).

**Table 4:** Awareness about motor development skills delay

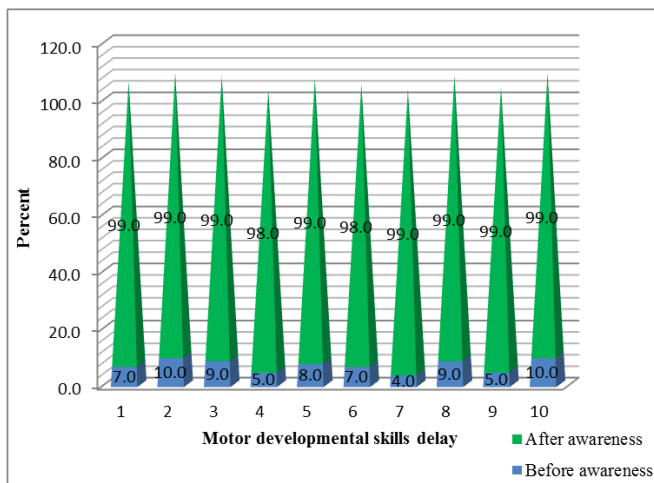
Aspects	Responses (n= 200 %)	
	Before Awareness Programme	After Awareness Programme
Hand or finger flapping	7	99
Head banging	10	99
Self mutilation	9	99
Toe walking	5	98
Smelling, banging, licking	8	99
Spinning objects	7	98
Attachment to unusual objects	4	99
Stubborn about rituals and routines	9	99
Restricted taste by consistency	5	99
Appear deaf or dumb	10	99

According to Murray and Piek (2004) who studied about Sensory-motor deficits in children with developmental coordination disorder (DCD), attention deficit hyperactivity disorder (ADHD) and autistic disorder, children who have been diagnosed with any one developmental disorder are very likely to meet diagnostic criteria for some other developmental disorder. Although comorbidity has long been acknowledged in childhood disorders, the importance of poor sensory-motor functioning in discriminating children with different disorders has been underestimated. Poor sensory-



motor coordination appears to be linked to developmental coordination disorder DCD, but not ADHD. Also, sensory-motor deficits in children with DCD and autistic disorder may provide insight into some of the social difficulties found in these groups of children.

Lovanne (2003) studied about effective educational practices for students with autism spectrum disorders. Students with autism spectrum disorders (ASD) present unique challenges to educators trying to plan effective instructional programs. Although an impressive body of research identifying effective practices has emerged, there have been minimal attempts to integrate the findings into a curricular foundation to be adopted by school districts. He emphasised the provision of a 6 core elements that have empirical support and should be included in any sound, comprehensive instructional program for students with ASD. These core elements are (a) individualized supports and services for students and families, (b) systematic instruction, (c) comprehensible/structured learning environments, (d) specialized curriculum content, (e) functional approach to problem behaviour, and (f) family involvement.



**Figure 4:** Awareness about motor developmental skills delay

Motor developmental skills delay:

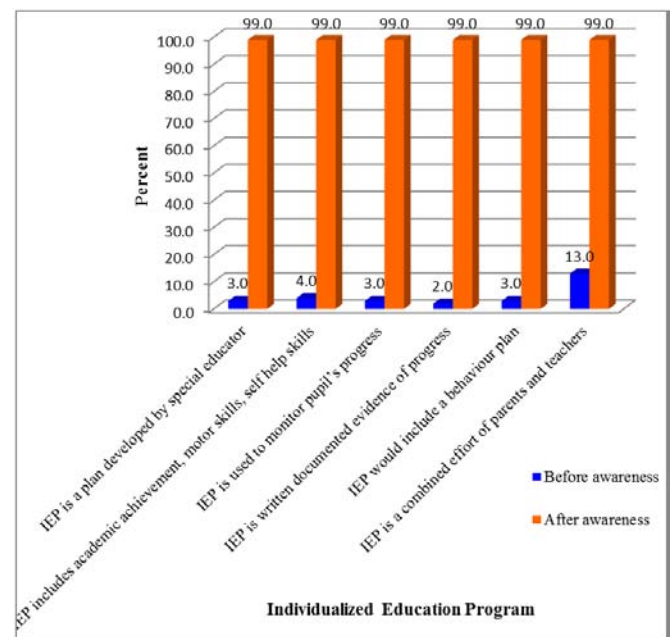
1. Hand or finger flapping
2. Head banging
3. Self mutilation
4. Toe walking
5. Smelling, banging, licking
6. Spinning objects
7. Attachment to unusual objects
8. Stubborn about rituals and routines
9. Restricted taste by consistency
10. Appear deaf or dumb

### 3.3 Awareness about Individualized Education Programme (IEP)

Individualized educational program are student specific, long term and essential for the student to be successful in meeting curriculum outcome and behaviour modifications. An IEP is developed if the parent and school based team decide that student cannot continue to be successful within the prescribed curriculum given good teaching practices (Guideline & standards, 2002).

**Table 5:** Awareness about Individualized Educational Programme

Aspects	Responses ( n= 200 %)	
	Before Awareness Programme	After Awareness Programme
IEP is a plan developed by special educator	3	99
IEP includes academic achievement, motor skills, self help skills	4	99
IEP is used to monitor pupil's progress	3	99
IEP is a written document Evidence	2	99
IEP would include behaviour plan	3	99
IEP is a combined effort of parents and teachers	13	99



**Figure 5:** Awareness about Individualized Educational Programme

## 11. Summary and Conclusion

Bringing a child with developmental disabilities (e.g., autism, blindness, cerebral palsy, dyslexia, mental retardation) into the world has life changing implications and lasting effects not only for the child, but also for her family (Martin and Colbert, 1997).

Symptoms of Autistic Spectrum Disorder can be present in a variety of combinations. Some people with the disorder have normal level of intelligence while most have same degree of intellectual disability ranging from mild to severe. Children in all categories of ASD have difficulties with social interaction and behaviour, but the extent and type of difficulty varies. They often respond to sensory stimuli in a typical manner. Assessment and diagnosis of ASD involves a multidisciplinary team. Parents need to be made aware of the aspects related to, social interaction difficulties, speech and language skills delay, developmental skills delay, motor developmental skills delay for early identification.

### **Awareness about social interaction difficulties**

After the awareness program 99 to 100 percent of sample knew aspects concerning social interaction difficulties of autistic children.

### **Awareness about speech and language skills delay**

- Before the awareness programme, 11 percent of the samples were aware that voice of autistic children was of high frequency than required, pulled parents when they required getting something and they could not sustain conversation.
- About 99 to 100 percent of the sample gained knowledge about the speech and language skills delay seen among autistic children.

### **Motor developmental skills delay**

- Before the awareness programme only 10 percent were aware that head banging and appearing to be deaf or dumb are motor developmental aspects seen in autistic children.
- After the awareness programme about 98 to 99 percent of the sample has gained knowledge about the various aspects of motor developmental skills delay.

### **Individualized Education Program (IEP)**

- Before the awareness programme, 13 percent of the samples were aware that IEP was a combined effort of parents and teachers.
- After the awareness programme 99 percent of the sample knew about IEP and the necessity to include behaviour modification plan, development of self help skills along with curriculum.

## **12. Conclusion**

To substantiate the statement, "Education is the key to awareness", the findings vividly reveals that the awareness programme has helped the parents to gain knowledge about social interaction difficulties. It is apparent that the parents have gained more knowledge about speech and language skills delay after the awareness programme. It can be inferred that the parents have gained more knowledge on developmental skills delay after the awareness programme. Parents have become more informed about motor developmental skills delay after the educational programme. The knowledge gained would prove beneficial for early identification of children with autism spectrum disorder in their families and surroundings as well. The knowledge about Individualised Education Program would provided them with awareness about the team involved in diagnosis and integration of the child in autistic spectrum to make them functional in the society

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