

## Autistic Children and the Society: A Case Study

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### Abstract

*Society is a complex phenomenon and many types of people are living here in many ways. It includes those autistic children who are living with us. Autism is not a mental disease. As we do not have any data in Bangladesh we can estimate that the numbers is not any less than that of India. Day by day their number is increasing alarmingly. They are facing a difficult reality from the mainstream society, who have always been cruel to people different from the majority. People with physical disabilities, in particular, face with an apathetic, uncaring environment that pushes them into a state of feeling redundant and unwanted. Despite the prejudice and lack of patronization many individuals have proven that with a little help they have much to offer to the society. People with disabilities are often defined by what they can't do as opposed to what they can. Could a person with disabilities have the courage to do something for his/her own profit or for the national and global development in the face of continuous obstacles and stigmatization? But they have some power of their own. To utilize the hidden power of the autistic children SWAC is working for 13 years. Having training and assistance from SWAC many of them are able to take part in different schools and the society and they are becoming able to do their daily activities independently. Their future is not fearsome; the earlier a diagnosis is made the better the chance of receiving appropriate help and support and better will be the prognosis.*

### Introduction

Autism is not a curse for the society. Autism is a lifelong developmental disability that manifests itself during the first three years of life. The rate of autism in all regions of the world is high and it has a tremendous impact on children, their families, communities and societies. About 70 million people are affected by autism worldwide (World Autism Awareness Day). The United Nations General Assembly unanimously declared 2 April as World Autism Awareness Day to highlight the need to help improve the lives of children and adults who suffer from the disorder so they can lead full and meaningful lives. UN Secretary-General Ban Ki-moon said that it is important to bring international attention to the disorder to end stigmatization, lack of awareness and inadequate support structures. People with **Autism Spectrum Disorder (ASD)** often have difficulties with social interaction, verbal and nonverbal communication and show repetitive behaviors. Autistic children bear with intellectual disability, difficulties in motor coordination and attention, and other health issues including gastrointestinal and sleep-related problems (Anderson, 2005). Neuro-chemical studies consistently find that there are increased blood levels of serotonin (5-HT) in people with autism (Anderson & Hoshino, 2005). Autism is thought to involve a broader condition that includes non-diagnosable social functioning deficits occurring in 10% to 20% of first degree relatives of a person with autism. This broader expression of autistic

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symptoms is not associated with mental retardation or epilepsy (Rutter, 2005). Autism is not considered to be one condition. It is thought to be many similar conditions resulting from different combinations of genes (Rutter, 2005).

The first signs are often seen in children between 12 and 18 months of age. Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 88 American children as on the autism spectrum—a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. An estimated 1 out of 54 boys and 1 in 252 girls are diagnosed with autism in the United States (<http://www.autismspeaks.org/what-autism>). Autism is associated with mental retardation in about 70% of cases (Fombonne, 2005). Approximately 65% of people diagnosed with autism also have anxiety and depression (Lainhart & Folstein, 1994; Klin, Mcpartland, & Volkmar, 2005). The areas of development that are often delayed in young children with autism include problems with nonverbal communication, social skills, verbal communication, selective visual attention to social cues, development of play skills and deficits in imitation and emulation abilities (Chawarska & Volkmar, 2005). Parents usually notice signs in the first two years of their child's life. The signs usually develop gradually, but some autistic children first develop more normally and then regress. Early behavioral or cognitive intervention can help autistic children gain self-care, social and communication skills. Although there is no known cure, there have been reported cases of children who recovered. Not many children with autism live independently after reaching adulthood, though some become successful.

### **Objectives of the study**

Research in the field is very rare because autism is unknown to the most people of Bangladesh.

- 1) To examine whether the autistic children are really disable to perform their daily activities.
- 2) To assess the possibility of their return to the mainstream society.

### **Methodology of the study**

It is a primary information observation based case study. To assess the changing behavior of the autistic children Society for the Welfare of the Autistic Children (SWAC) was visited four (4) times and the students of SWAC were observed for one (1) year.

### **What is Autism**

The word 'Autism' has come from Greek word 'autos' that means 'self' (12<sup>th</sup> annual volume of SWAC). In 1943 U.S.A. child psychiatrist Leo Caner at first used the word autism. Autism is a lifelong developmental disability, which affects the way a person communicates and relates to people around him. Individuals with autism are unable to relate to others in a meaningful way. Their ability to develop friendship is impaired as is their capacity to understand other people's

feelings and thoughts. Individuals with autism can have accompanying learning disabilities but everyone with the condition shares a difficulty in making sense of the world ([www.autism-swac.org](http://www.autism-swac.org)).

Autism is a neurological disorder that can impair communication, socialization and behavior. The prevalence of autism is about 1–2 per 1,000 people worldwide, and it occurs about four times more often in boys than girls (CJ, Croen LA, Daniels, 2007). However, some types of Autism may not be diagnosed until years later when the child enters school, due to late occurring of social deficits or difficulty in playing with others. When this occurs, the child is usually too old to take advantage of early childhood intervention services and is evaluated for entry into the special education system (world awareness day).

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome (<http://www.autismspeaks.org/what-autism>).

The Centers for Disease Control and Prevention (CDC) report 20 per 1,000 children in the United States are diagnosed with ASD as of 2012, up from 11 per 1,000 in 2008 (Stephen J. Blumberg, 2013). The number of people diagnosed with autism has been increasing dramatically since the 1980s, partly due to changes in diagnostic practice and government-subsidized financial incentives for named diagnoses; the question of whether actual prevalence has increased is unresolved (CJ, Croen LA, Daniels, 2007). In rare cases, autism is strongly associated with agents that cause birth defects. Controversies surround other proposed environmental causes, such as heavy metals, pesticides or childhood vaccines. The vaccine hypotheses are biologically implausible and lack convincing scientific evidence.

### **Identifiable manner of autistic children**

Overt symptoms gradually begin after the age of six months, become established by age two or three years, and tend to continue through adulthood, although often in more muted form. It is distinguished not by a single symptom, but by a characteristic triad of symptoms: impairments in social interaction; impairments in verbal and non-verbal communication; and restricted and repetitive patterns of behavior or interest. These three types of problems are called ‘triad of impairment’. According to ‘American Psychiatric Association’ 1994, the identifiable manners of autistic children are:

1. Lack of imaginative play,
2. Attention problems,
3. Repeated body movement,

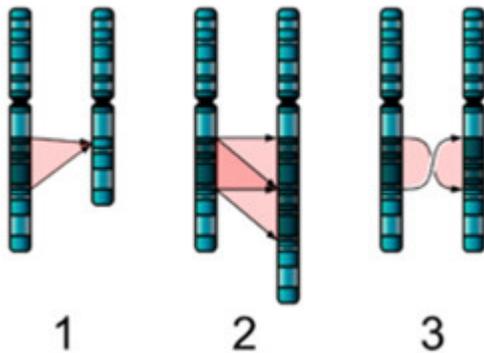
4. Failure to point at objects,
5. Lack of interest in peers,
6. Lack of eye contact,
7. Disruptive, aggressive or self-injurious behavior,
8. Apparent insensitivity to physical dangers and pain,
9. Resistance to any change in routine,
10. Unusual attachment to objects,

Other symptoms of autistic children are as follows:

Autistic children may have symptoms that are independent of the diagnosis, but that can affect the children or the family. An estimated 0.5% to 10% of individuals with ASD show unusual abilities, ranging from splinter skills such as the memorization of trivia to the extraordinarily rare talents of prodigious autistic savants (Treffert DA., 2009). Many individuals with ASD show superior skills in perception and attention, relative to the general population. Sensory abnormalities are found in over 90% of those with autism, and are considered core features by some (Grant K, Davis G., 2009).

### Causes of Autism

There is a common cause at the genetic, cognitive, and neural levels for autism's characteristic triad of symptoms. However, there is increasing suspicion that autism is instead a complex disorder whose core aspects have distinct causes that often co-occur.



Deletion (1), duplication (2) and inversion (3) are all chromosome abnormalities that have been implicated in autism. The large number of autistic individuals with unaffected family members may result from copy number variations—spontaneous deletions or duplications in genetic material during meiosis (Cook EH, Scherer SW. 2008). Autism has a strong genetic basis. Complexity arises due to interactions among multiple genes, the environment, and epigenetic factors which do not change DNA but are heritable and influence gene expression (Rapin I., 2008). Studies of twins suggest that heritability is 0.7 for autism and as high as 0.9 for ASD, and

siblings of those with autism are about 25 times more likely to be autistic than the general population (Geschwind DH., 2009).

Parents may first become aware of autistic symptoms in their child around the time of a routine vaccination. This has led to unsupported theories blaming vaccine "overload", a vaccine preservative or the MMR vaccine for causing autism (Gerber JS, 2009). The latter theory was supported by litigation-funded study that has since been shown to have been "an elaborate fraud"(Godlee F, Smith J, Marcovitch H. 2011). Although these theories lack convincing scientific evidence and are biologically implausible, parental concern about a potential vaccine link with autism has led to lower rates of childhood immunizations, outbreaks of previously-controlled childhood diseases in some countries, and the preventable deaths of several children (McBrien J, Murphy J, Gill D, 2003). Parents of children with ASD have higher levels of stress. Siblings of children with ASD report greater admiration of and less conflict with the affected siblings than siblings of unaffected children or those with Down syndrome. Most professionals believe that race, ethnicity and socioeconomic background do not affect the occurrence of autism ([www.bracbank.com/autism](http://www.bracbank.com/autism)).

### Case study

The Society for the welfare of Autistic Children (SWAC) was formed on 3 February, 2000 by a group of very enthusiastic devoted parents of individuals with autism. The aim of SWAC is educating and training individuals with autism to develop to their fullest potential. It is registered with the Social Welfare Department under Societies Act of the Government of the People's Republic of Bangladesh. SWAC aims to improve the quality of life of individuals with autism and their families. Services include diagnosis, assessment, clinical facilities, education, vocational training, package program, adult work and activity program, home rehabilitation program and residential facility. SWAC also aims to provide counseling and training to parents of individuals with autism, set up a resource centre, raise awareness in order to create better understanding of autism throughout the country and lobby to the government in order to establish the rights of individuals with autism.

SWAC runs a training and education centre which has a highly structured program and places importance on individual caring. About 50 students are observed. During the admission time, their total condition is examined and according to their obstacles they are sent to concerned section. The student and teacher ratio during training is 2:1. This is essential for individuals with autism. Emphasis is given on developing communication and social skills, primary and secondary education, acceptable behavioral patterns and self ruling skills. SWAC has about 116 students. These students are divided according to their abilities and age. At the very initial stage the ratio of teacher and student is 1:1. And after serving, observing and educating the students the ratio is 1:2. SWAC provides intensive individualized instruction to individuals with autism, **targeting the broad range of educational, behavioral, social, communication, daily living cognitive and motor dysfunctions that affect them, in a single integrated setting.** Each autistic child's sensitivity is different, so specific care is taken to keep a safe and healthy indoor environment,

where students may function at their very best. The main teaching methodology (ABA Method) employed has been scientifically validated and is based on the principles of behavior analysis. **Applied Behaviour Analysis (ABA therapy)** is a generic term for a widely used scientific method of behaviour modification. ABA therapy techniques have been proven in many studies as the method of choice for treating deficits in the behaviors of children with Autism Spectrum Disorder (ASD) at any level. ABA therapy approaches such Pivotal Response Treatment (PRT), Picture Exchange Communication System (PECS), Self-Management, and a range of social skills training techniques are all critical in teaching children with autism. Ultimately, the goal is to find a way of motivating the child and using a number of different strategies and positive reinforcement techniques to ensure that the sessions are enjoyable and productive. ABA Therapy helps to establish better eye contact and encourages learning and staying on task. Finally the children acquire the ability and the desire to learn and to do well. Even if the child does not achieve a “best outcome” result of normal functioning levels in all areas, nearly all autistic children benefit from early intensive ABA programs. Through the practice of daily assessment of progress towards individual goals, teachers can keep track of the student’s progress. Data analysis permits the team to make changes in each student’s program in order to achieve maximum progress. Morning Shift students attend classes from 8.30am to 1pm. senior students attend classes until 2.00 pm. Preparatory students attend classes until 4pm. Day shift is from 2 pm to 6.00 pm.

SWAC has about 30 rooms in accordance with the variety of autistic children:

**Vocational training-preparatory work and activity room:** Its main focus is on functional education and training to prepare the students for adult life. The students work on paper technology, Jewelry, paper print- bags, envelops, gift wrap, Textile print- block, tie dye, sewing, Art, Card. Autistic children are taught by vocal training, arrange their name from puzzle words, and identify their name plate etc activities are taken to assess their merit and ability.

**Cafeteria room:** In this room they are taught how to prepare food, wash dishes, take orders, serve food, clean tables, take payment and give receipt. But they are always under the teacher’s supervision.

**Occupational and Sensory therapy room:** Occupational and Sensory therapy is a scientific approach. Here students who are backward in merit, physical growth and mental development, are given treatment by different equipment. For example, some students are not able to hold the pen and some doesn’t like to keep dress on his body, so to increase his body’s accessibility, his sense or feeling related treatment is given by body touching machine. As a result his sense/ feeling are increasing day by day.

**Computer classes:** Here students are learning different computer programs like typing, printing, laminating, and photocopying perforating and filing documents; distributing notices and letters etc activities. Computer courses are given to enhance their learning capability.

**Early stage room:** Here autistic children are learning how to follow command, how to communicate with others. And as a result their speech, vocal power, communication way is developed.

**Junior section room:** In this room student's age limit is 7-8 years. They are taught the same education of play group, Nursery.

**Early intervention centre:** Each student has a comprehensive individualized plan of instructions which is an integrated assessment of the student's needs across all disciplines. The team on a weekly basis reviews the plan. Parents are kept abreast of their child's progress through quarterly parent teacher meetings. Parents are spending at least one whole day in their child's classroom to observe firsthand the teaching techniques. Parents are requested to follow the teaching techniques while the students are staying at home. A parent said that her son named Hasib could not talk and he is attending SWAC for 7 years. Now Hasib can talk clearly.

**Laundry room:** To make them self- dependent, clothing, washing, and ironing are taught. As a result they do their daily work from time to time. Even after finishing their Tiffin, they are becoming used to wash their Tiffin box.

**Wash room:** Here they are taught how to brush their teeth and related daily activities.

**Music room:** Most of them are interested for cultural activities like singing, dancing etc. As a result their speech develops and it refreshes their mind.

**Kitchen room:** Here students are taught how to cook noodles, cake, biscuits and other handmade food by hand to hand approach.

**Professional section:** Here students are trained different handmade products like stitch, block, making packet, paper activity, wrapping paper etc. And these products are selling to the market.

**Nursery section:** Plant trees, water plant, paint tubs etc works are done by them as their daily task.

**Outgoing program:** Each month SWAC students are taken out to places such as zoo, museums, historical places, Chinese restaurants, ice-cream parlors, amusement parks, supermarkets etc. on an educational tour. These education programs improve their socialization skills and teach them how to behave in public, concept of money, table manners and to become aware of their environment and learn about nature, our culture and history.

**Birthday program:** Students birthday are celebrated at school to make them feel special and learn to give and take. This type of programs are arranged to make them social.

**Sports:** Sports events are arranged annually. It enhances their body functioning activity. Sports and cultural activities must be ensured for their mental and physical flourishing.

**Home rehabilitation program:** The psychologist and teachers visit the student's home in order to assess each student's home environment set up and give suggestions to parent on how to educate and train their child at home.

Besides these, SWAC has dormitory for students and teachers, gymnasium, swimming pool, library, bakery.

**Parent programs:** Parent teacher meetings are held every three months to discuss the student's progress and deliver their reports.

**Teacher training:** Teacher training is arranged thrice a week. Trainers from abroad provide training once a year. When the Prerona Project began in 2007, SWAC management and teachers began to receive practical autism training in Bangladesh from Finnish autism experts. Since then, these experts have been conducting hands-on autism trainings on a regular basis for the teachers and parents of SWAC. These workshops and practical training programs have given teachers the opportunity to compare their activities with that of autism organizations in developed countries. Through those training programs, SWAC teachers developed many skills including how to create structured schedules and environments, how to use techniques such as visualization and PECS (Picture Exchange Communication System) and how to develop IEPs according to the needs of children and adults with autism. At the moment, SWAC is playing a significant role in changing attitudes about autism throughout the country.

After taking part in the SWAC many autistic students are able to adjust themselves to the mainstream society and schools. Some of them are:

Name	Age	Class	Present School
Tousif Bin Kashem	14	(iii)	B.C.H.I.R. School and College
Montasir Sames	8	(ii)	Ananda Nikaton European School
Jarif Mahadi	15	(v)	Dhaka Tutorial
Fariza Eshal Nodi	5	Nursury	Tiney Taughts
Zaim Marur	8	K.G. 2	Academics
Eshan fajjal Ahmed	7	Play Group	Udoyon International School and College
Tanvir Anjum	5	Play Group	Padegozy

It is observed that those students are identified as autistic at the very early stage, only in that case they are able to get fit for the mainstream society. But in the case of late identified students, it takes about 6-7 years to improve their conditions. Sometimes it takes a life time to overcome this obstacle. So, parents' awareness about autism is very essential.

The school staff includes professionals from the disciplines of psychology and occupational therapy. Each student has a comprehensive individualized plan of instructions, which is an integrated assessment of the student's needs across all disciplines. The team on a weekly basis reviews the plan. Parents are kept abreast of their child's progress through quarterly parent teacher meetings. They are also expected to commit to spending at least one whole day in their child's classroom to observe firsthand the teaching techniques.

Other activities of SWAC are as follows:

- Utilizing all the autism knowledge of the personnel,
- Empowerment and inclusion of the minorities,
- Functional parent network and home rehabilitation activities,
- An educational, handicraft centre for children and adults with autism and other disabilities at indigenous community in the Rangamati, CHTs,
- Training program, thematic and participatory workshop for parents,
- Provide speech and language therapy, occupational and sensory therapy and music therapy to the individuals with autism.

In this regard, it is seen that SWAC aims to improve the quality of life of individuals with autism and their families. Services include diagnosis, assessment, clinical facilities, education, vocational training, package program, adult work and activity program, home rehabilitation program and residential facility. SWAC also create employment opportunities inside and outside SWAC enabling them to participate and integrate in society. It provides special education and training to individuals with autism starting from preschool age with planned growth up to adulthood. It also integrates high functioning children with autism into mainstream schools.

Main focus point is school holidays are kept to a minimum.

SWAC emphasizes on Life management skills, independent skills, and behavioral skills of the autistic children.

### **Parent activities**

- Diagnosis and assessment of children with autism,
- Vocational training-Preparatory work and Activities,
- Participate in outing program,
- Parent counseling,
- Parent training programs etc.

### **Findings of the study**

After observing the autistic children about one year it is found that:

1. They become very much regular and punctual.
2. They are able to do their daily self-care activities and extra activities such as music. Art, drawing, paintings, dancing, acting etc.
3. Respect to others, obligations, thanking sense etc. factor are growing among them.
4. Day by day their social communication sense is growing up.
5. Most of them are becoming a successful person in the main stream society after completing their training.
6. Most of them are cultural minded.

### **Conclusion and recommendations**

According to the social model of disability, autistic children are facing suppression, neglect attitude and mentality from the main stream society. Society is a chain for them. If they are female, then they have to face 'double disability'. Autistic children are not sick, if they are identified at the very early stage, they can be cured. And the society will get the power hidden behind them. In this regard, **motivation, care, love, training, treatment** are recommended. In order to establish the rights of the individuals with autism, lobby to the government is essential. The physically-challenged people will have to be groomed through more affection and love by other people as they are an integral part of our society. Parents' participation and some necessary tips are very much vital to getting back the autistic children to the society. Awareness raising campaigns nationwide is essential because internationally the autistic day is celebrated only from 2007. No single treatment is best and treatment is typically tailored to the child's needs. Families

and the educational system are the main resource for treatment. Intensive and sustained special education programs and behavior therapy early in life can help children acquire self-care, social and job skills, and often improve functioning and decrease symptom severity and maladaptive behaviors; claims that intervention by around age three years is crucial are not substantiated. Educational interventions can be effective to varying degrees in most children. Many medications are used to treat ASD symptoms that interfere with integrating a child into home or school when behavioral treatment fails. The aim of SWAC is to develop excellent facilities for the special education, training and rehabilitation of individuals with autism within a structured, happy and caring environment allowing them to grow in confidence and independence, to feel safe and secure and to achieve their maximum potential. Create employment opportunities inside and outside SWAC enabling them to participate and integrate in society.

There is no magical cure for autism. Early diagnosis and intensive behavioral intervention in optimal educational settings can have a significant, positive and lasting impact on children with autism. They can benefit from placement in a good educational program. With intensive intervention, many children diagnosed with the disorder before the age of 5 go on to attend mainstream school. Proper evaluation of each child's strengths and limitations, appropriate training and an autism friendly environment can help them to perform to their maximum potential. Mass awareness campaign through newspaper, radio, TV and other media in order to create better understanding about autism among the public and professionals throughout the country, organize surveys all over the country to collect data about the number of individuals with autism in Bangladesh, arrange parent counseling, arrange international standard training programs for teachers, professionals, parents and careers, provide special education and training to individuals with autism starting from preschool age, integrate high functioning children with autism into mainstream schools. Prime Minister Sheikh Hasina said that, "The physically-challenged people, particularly autistic children, are in no way a burden; rather they are precious assets of the country. So, we would do whatever necessary for flourishing their latent talents" (The Daily Ittefaq, April, 2013).

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