

Current Status of Service Centers Serving Autism Spectrum Disorder in Dhaka City

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Abstract

This cross-sectional study was designed to understand the current status of service centers serving autism spectrum disorder in Dhaka city. Results show that there are three such centers that purely serving autistic children in Dhaka city. Students in SWAC- total students 116, male-99, female-17, teachers-49, specialists-2 and other staff-19; in AWF total students-155, male-126, female-29, teachers-62, specialists-3, other staff-15; in ACWF total students-30, male- 25, female-05, teachers-23, specialists -3, other staff -8. Common activities are diagnosis and assessment of autistic children, daily life skill training, vocational training, package program, outing program, nursery program, parent counseling and training program, teachers training program, integration of high functioning autistic children into normal schools, home visit program, free treatment, seminars and workshops, periodical review, awareness program, rehabilitation of young and trained autistic children, residential training. Common tools are training materials such as chair, table, board, different types of wooden and plastic toys, drawing board, color pencils, art paper etc; musical instrument like harmonium, guitar, tabla etc; for technical training computer, different categories of books, papers, magazines etc; for parents, care givers and for general people brushier, newsletters, magazine etc; for physical training trade mail, basket ball, football, rings, swings etc. Technologies used in these centers are computer, internet, developed website, telephone services etc. Financial source mainly from student's fees. SWAC -admission fees 8000-10000tk, monthly fees 3500-5000tk; AWF-admission fees-8000-10000tk, monthly fees-2400-4200tk; ACWF-admission fees: 7000-10000tk, monthly fees-1800-3200tk. These are mainly non-government, non-profitable, non-political and voluntary organizations. These centers are only registered under Social and Welfare Ministry. Policy guideline for smooth running of these centers was not available. Future planning of these organizations are to create mass awareness, collect data about the number of autistic children in Bangladesh, establish own complex, contact with local, national and international organizations, create job opportunities, establish residential facility, free treatment and education of underprivileged children, training centre to train professionals, parents, care givers etc.

Key words: autism, autism spectrum disorder (ASD), vocational, cafeteria.

Introduction

Autism is a lifelong developmental disability, which affects the way a person communicates and relates to people around him that was identified in 1943 but it still remains an unknown one in Bangladesh. Autism typically appears during the first three years of life. It is not a mental illness.

Autism affects one person in 250 in our neighboring country India making it more common than Down syndrome or Childhood Cancer. As we do not have any data in Bangladesh we can estimate that the numbers here will be no less than India and increasing in an alarming rate. According to 'American Psychiatric Association' 1994, the core defining features of autism are: Impairments in socialization, impairments in verbal and non-verbal communication, lack of imaginative play, attention problems, repeated body movement (hand flapping, rocking, etc.), unusual attachment to objects, resistance in any change in routine, apparent insensitivity to physical dangers and pain, disruptive, aggressive or self-injurious behavior, lack of eye contact, lack of interest in peers, failure to point at objects.¹ Male to female ratio is 3: 1 to 4: 1.² There is no cure for autism. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. Most professionals agree that the earlier the intervention, the better.³

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It is estimated by the Ministry of Social Welfare that the total number of persons with autism spectrum disorders (ASD), could be as high as 1, 4 million -- of whom only a few hundred have been diagnosed. The general attitude towards autism is mostly negative and it is seen as a social barrier. Even today, autism is considered a God-given curse and children with autism spectrum disorders (ASD) are taken as possessed by the Devil. Also bad parenting is accused: mothers going out to work still get the blame.⁴ In Bangladesh, Ministry of Social Welfare is the lead Ministry and acts as the coordinating agency for Government and Non-government interventions towards addressing disability issues. In the recent time dynamic and sustainable steps have been taken for the Programmes for the Person with Disabilities (PWDs). The steps are:

I. To establish separate ticket counters in railway station, bus terminals, river ports, steamer terminals, airports and airway offices to facilitate easy availability of tickets for the PWDs.

II. To maintain reserve seats in the bus, train and water transports for PWDs.

III. To fill up the 10 percent reserved quota for employment in the government jobs by the orphans and PWDs.

IV. To construct a ramp in all the government offices to facilitate easy movement of the PWDs.

V. To withdraw the existing restrictions regarding appointment of PWDs in the Govt. class I & class II jobs.

VI. To arrange micro-credit for PWDs by all the Nationalized Commercial Banks (NCBs).⁵

Rationale/ justification

This study was conducted to raise the standard of support and services for people with ASD across the country and internationally. Deliver a range of information, advice, advocacy, training, assessment and diagnostic services to people living with autism. Provide a hub for a networked autism community, both in the country and internationally, to facilitate sharing of knowledge and enable better linking of public need to professional expertise. To improve education, communication, and social abilities of children with autism so that they may join their typically developing peers in community environments and class rooms.

To develop a network of consistently outstanding and innovative outreach centers for autism which not only provides help and support to individuals with autism but also to their families and those involved with their care, support, ongoing education. To assess the activities of the centers, to find out the tools, logistics, technologies available in the centers, find out the financial sources, explore the government policy of the centers, ascertain the limitations, constraints and scopes of the centers for autism.

Aim of the study

To find out the current status of centers serving autism children in Dhaka city.

Methods and Materials

This was a descriptive type of cross sectional study conducted in three centers of autistic children in Dhaka city where these centers provide only services for autistic children. The centers are Society for the Welfare of Autistic Children (SWAC), Autism Welfare Foundation (AWF), and Autistic Children Welfare Foundation (ACWF). The period of this study was six months from January 2012 to June 2012. Relevant all documents about autism spectrum disorder were collected, reviewed and gathered all information. Before performing the study, consent from the appropriate authorities was taken. No activity was performed which may harm the religious or social values or norms during the study. Some information was collected using interview administered questionnaire. The data were analyzed and results are as follows:

Results

Centers for serving autistic children:

Three centers solely serving autism spectrum disorder in Dhaka city are:

1. Society for the Welfare of Autistic Children (SWAC)
Address: 70/ka, Pisciculture, Shayamoli, Dhaka.

Established on 3rd February, 2000. It is registered with the Social Welfare Department under Societies Act of Government of the People's Republic of Bangladesh. Registration number is Dha-06127 dated 30 April, 2001.

2. Autism Welfare Foundation (AWF)
Address: House No: 38/40, Road no: 4, kha block, Pisciculture Housing Society, Mohammadpur, Dhaka.
Established on 4th April, 2004.

3. Autistic Children Welfare Foundation (ACWF)
Address: House No: 74, Lane: 3, Block-E, Mirpur-12, Dhaka-1216.
Established in 2007.

Table 1: Total number of autistic children

Name of the organization	Male	Female	Total
Society for the welfare of autistic children(SWAC)	99	17	116
Autism welfare foundation(AWF)	126	29	155
Autistic children welfare foundation(ACWF)	5	25	30
Total	230	71	301

Table 2: Work force

Name of the organization	Teacher	Specialist	Other staff	Total
Society for the welfare of autistic children(SWAC)	49	2	19	70
Autism welfare foundation(AWF)	62	3	15	80
Autistic children welfare foundation(ACWF)	23	3	8	34
Total	134	8	42	184

Activities:

- Diagnosis and assessment of autistic children
- Daily life skill training and special education
- Vocational training
- Package program
- Outing program
- Nursery program
- Parent counseling
- Parent training program
- Teachers training program
- Integration of high functioning autistic children into normal schools
- Home visit program
- Free treatment
- Seminars and workshops
- Periodical review

- Awareness program
- Rehabilitation of young and trained autistic children
- Residential training
- Cafeteria program
- Annual magazine and newsletters
- Underprivileged program
- Secretarial work

Common tools:

- Training materials such as chair, table, board, different types of wooden and plastic toys, drawing board, color pencils, art paper etc.
- Musical instrument like harmonium, guitar, tabla etc.
- For technical training - computer, books, papers, magazines etc.
- For parents, care givers and general people brushier, newsletters, magazine etc.
- For physical training trade mail, basket ball, football, rings, swings etc.

Technologies:

Limited technologies are as:

- Computer
- Internet
- Develop website
- Telephone services
- But website of AWF was not available during this study.

Financial source:

Financial source of these organizations is not clear .They run their organization mainly from student's fees.

Table 3 : Organizations with student fees

Name of the organizations	Admission fees (Taka)	Monthly fees (Taka)
Society for the Welfare of Autistic Children (SWAC)	8,000- 10,000	3500-5000
Autism Welfare Foundation (AWF)	8,000- 10,000	2500- 4200
Autistic Children Welfare Foundation (ACWF)	7,000- 10,000	1800 – 3200

Tuition fees of autistic children depend on the severity of the symptoms. It also depends on the financial condition of the family. Some students get services free of cost (underprivileged children).

Government policy:

These are mainly non-government, non-profitable, non-political and voluntary organizations. There is no government policy for these centers. These centers are only registered under Social and Welfare Ministry. Policy guideline for smooth running of these centers was not available.

Limitations:

- Limited fund: they have no own complex to provide facilities.
- Limited space: they cannot afford all the children coming to these organizations.
- Limited trained professionals
- Limited machinery and tools: For the autistic children and the centre.
- Lack of social awareness.

Discussion

Present scenario in Bangladesh:

The identification and treatment of children with Autism in Bangladesh was confined to a few Medical College Hospitals and Post Graduate Institutes. Even doctors are not aware of the clinical features of Autism and its management and sometimes cannot understand the disorder. The services for children with Autism was visually reflected from 1990 in Dhaka Shishu Hospital and other hospitals and subsequently many other organizations like the Society for the Welfare of Autistic Children (SWAC), Autistic Welfare Foundation (AWF), Autistic Children Welfare Foundation (ACWF) and others came forward with their activities for autistic children from the year 2000 and onward. With the establishment of the Centre for Neurodevelopment & Autism in children in Bangabandhu Sheikh Mujib Medical University (BSMMU) awareness for Autism boosted in Bangladesh.

Challenges for Bangladesh:

Due to lack of trained professionals we are unable to reach autistic children. They don't have easy access to a tertiary level hospital. Not all doctors at Upazila and District level are educated on autism. So misdiagnosis and mistreatment still occurs. Another challenge that has to be overcome is in education.

Autistic children have difficulties entering normal schools, even if they are capable intellectually and have relatively "good" behavior. Most schools are reluctant to have autistic students; they foresee many difficulties in handling and teaching autistic children. There are no curriculums for training of teachers of autistic children, by government and private institutions. Even there is no facility for short-term training for teachers of autistic children. Late diagnosis of autism in children occurs due to poor awareness regarding autism among many doctors. And even of those doctors screening children with autism, many do not know to whom to refer their patients. The case is more acute for under-privileged autistic children.

Conclusion and recommendations

Children with Autism are special need students. They have the right to the services and supports as specified in their Individualized Educational Program (IEP).

- Learning methodology, learning environment, learning opportunity, and learning community must be integrated into the system of education.

- On the basis of relevant educational research and curriculum, the projects would have to be developed and carried out.

- Development of administrative structures.

- Bangladesh action plan for Children with Autism should have training Program for parents as early intervention, sensory integration; involve home and community to gain learning experience and performance of Autistic child.

- Provide materials, visual support, TEACCH(Treatment and Education of Autistic and related Communication-Handicapped Children), PECS(Picture Exchange Communication System), social story, power card, computers with Internet access, CAI(Computer Aid Instruction) for repeat practice by 3'R technique (Routine repeat Relax) reinforcement by a special education team.

- Community Based Rehabilitation (CBR) to support community.

- Promoting autism Education in Bangladesh based on law and government policy.

- Development of a legal framework and national plans for autism.

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