

Integration of Health Care and Social Support in Specialized School for Children with Autism: A Case Study from Dhaka City

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Abstract

Autism spectrum disorders (ASD) are complex cognitive and neuro-behavioral disorders that affect a person's ability to communicate, to form relationships with others and to respond appropriately to the environment. This spectrum of disorder includes – Childhood autism, Asperger's syndrome, Rett's syndrome etc. Worldwide 1 in 160 children are affected with autism which begin in childhood and persists into adolescents and adulthood. Some people with ASD live independently and others have severe disabilities. Some need lifelong care and support. This study aimed to explore the methodology of developing the children with autism and other disabilities by the specialized school and also to find out the benefits of integration of health care and social support system in the regular activities of such schools. As the children with autism are mostly associated with some diseases which need regular assessment and health care for which integration of health care and social support would provide positive impact. This was an observational study carried out from March to August 2018 in a specialized school for children with autism and other disabilities. Data were collected from passive observation, informal discussions with the school authority and participating formal workshop and discussion sessions carried out by the school. Descriptive qualitative analysis was done to get the results of the study. This school follows one teacher for one student methodology to develop the life skills and day to day activities of the children and provide regular occupational therapy, speech and language therapy, psychotherapy, vocational training, music and dance therapy, teach cycling, swimming and provide computer training. They conduct regular

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training session for the teachers and parents. They have developed collaboration with a nearby hospital that is committed to provide free health care support, doctor consultation, and dental care with minimum waiting time on priority basis. The school arranges regular nutritional assessment of these children with expert dietician. The school has also developed a parent teacher association to ensure the social support system for these special children. Besides the regular school activities, the integration of health care and social support is providing a positive thrust to the development of these children and improving their social acceptance.

Key Words: Children with Autism, health care, social support, specialized school, Dhaka city

Introduction

Autism or Autism Spectrum Disorder (ASD) is a group of neurodevelopmental disorders which have complex cognitive and neurobehavioral problems and affects a person in a multi-dimensional ways (Wing, 1996). ASD affects a person's ability to communicate with others, to form relationship with surrounding people even family members and to respond appropriately to the environment (American Psychiatric Association, APA, 2013). ASD are diagnosed with increasing frequency (Courtney & Messerschmidt, 2013). According to World Health Organization (2017), "1 in 160 children has an autism spectrum disorder (ASD). ASDs begin in childhood and tend to persist into adolescence and adulthood. While some people with ASD can live independently, others have severe disabilities and require life-long care and support. Evidence-based psychosocial interventions, such as behavioural treatment and parent skills training programmes, can reduce difficulties in communication and social behaviour, with a positive impact on wellbeing and quality of life for persons with ASD and their caregivers. Interventions for people with ASD need to be accompanied by broader actions for making physical, social and attitudinal environments more accessible, inclusive and supportive. Worldwide, people with ASD are often subject to stigma, discrimination and human rights violations. Globally, access to services and support for people with ASD is inadequate."

Background

Autism described as a spectrum, has only recently been given the name Autism Spectrum Disorder (ASD) in the fifth edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5; American Psychiatric Association, 2013). According to National Institute of Health, (2018), "Autism spectrum disorder (ASD) refers to a group of complex

neurodevelopment disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction. The symptoms are present from early childhood and affect daily functioning. The term spectrum refers to the wide range of symptoms, skills, and levels of disability in functioning that can occur in people with ASD. Some children and adults with ASD are fully able to perform all activities of daily living while others require substantial support to perform basic activities. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, published in 2013) includes Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS) as part of ASD rather than as separate disorders. A diagnosis of ASD includes an assessment of intellectual disability and language impairment. ASD occurs in every racial and ethnic group, and across all socioeconomic levels. However, boys are significantly more likely to develop ASD than girls. The latest analysis from the Centers for Disease Control and Prevention estimates that 1 in 68 children have ASD.” According to Baird, G., et. al., (2006) prevalence of autism and related ASDs are substantially greater than previously recognized. The reported prevalence of ASD in South Asia ranged from 0.09% in India to 1.07% in Sri Lanka that indicates up to one in 93 children have ASD in this region. Alarming high prevalence (3%) was reported in Dhaka city. Study sample sizes ranged from 374 in Sri Lanka to 18,480 in India. The age range varied between 1 and 30 years (Hossain, M. D., 2017).

NIH also stated that some genetic disorders are associated with an increased risk for autism, including Fragile X syndrome and tuberous sclerosis which results from a mutation in a single, but different, gene. While each of these disorders is rare, in aggregate, they may account for 20 percent or more of all autism cases. People with ASD also have a higher than average risk of having epilepsy. About 20 to 30 percent of children with ASD develop epilepsy by the time they reach adulthood. (NIH, 2018) apart from these autism is also sometimes associated with other co morbid disorders like attention deficit hyperactivity disorder (ADHD), generalized anxiety disorder (GAD), mood alteration etc (Simonoff et al., 2008). Diagnosis of ASD is based on DSM-IV-TR or DSM-V criteria (Julie, A. Worley, J. L. Matson, 2012). Diagnosis is also based on Social Responsiveness Scale (SRS) and Social Communication Questionnaire (SCQ), Social imagination, Diagnostic Interview for Social and Communication Disorders (DISCO Signposting set) (Frazier, T.W. et. al., 2012; Carrington, S. et. al., 2015).

Along with diagnosis of autism, it is also very important to diagnose of the associated disorders and to treat them simultaneously otherwise

according to some studies co morbid conditions can lead to greater impairments and slow down the development of the child ((Gadow, Guttman-Steinmetz, Rieffe, & Devincent, 2004 & 2012). Previous studies have documented a high level of functional limitations and poor health status in children with autism, an accompanying high level of health care use and unmet health needs, and increased parenting stress and family burden. (Kogan, M. D. et. al., 2008 & 2009; Boulet, S.L et. al., 2009; Schieve, L.A., 2007). Studies suggested that Parents of low-income countries experience a social stigma for having a child with Autism Spectrum Disorder or mental illness. They encounter social discrimination and experience increased levels of parental stress (Soron, T. R., 2015).

Objectives

This study aimed to explore the methodology of developing the children with autism and other disabilities by the specialized school and also to find out the benefits of integration of health care and social support system in the regular activities of such schools.

Theoretical framework

As the children with autism are mostly associated with some diseases which need regular assessment and health care for which integration of health care and social support would provide positive impact.

Methodology

This was a qualitative study carried out from March to August 2018 in a specialized school for children with autism and other disabilities. The school is Smiling Children Special School (SCSS) which is situated in Aftabnagar under Badda Thana of Dhaka city. SCSS is a specialized school for children with autism and other physically and mentally disabled children. Data were collected from passive observation of the school's day to day activities with the children, informal discussions with the school authority, and teachers of the school, parents of the children and participating formal workshop and discussion sessions carried out by the school. In-depth interview of the Principal of the school was taken finally to get a larger picture of the school and it's students. Descriptive qualitative analysis was done to get the results of the study.

Key Findings

Establishment of the School

The Smiling Children Special School (SCSS) was established in 2010 in Dhaka at Badda Link Road with only four students and seven teacher and staff altogether with empathy for the special need children. The Founder

Principal of the school along with some other likeminded persons was devoted to establish a school for children with autism and other disabilities. The motivation behind such will was all of them had a special need child in their family and to fulfill their need of education and other life skills development. Having academic degree on special education and training on autism from national and international institutions, and working in different schools for special need children for more than five years, the founder principal of SCSS developed the expertise to start this school. The financial support came from the families of the founders and other individual donors. Within one year of establishment the number of students raised to thirty five.

Socio Economic Characteristics of the Students

The students coming to SCSS are mostly from higher middle class or higher class families. Most of the families have their own house or flat and private car and their income source is mostly family business or higher level official job. The monthly expenditure for the student at the school varies from ten to fifteen thousand taka per month except travelling or tiffin cost or medication cost. It is not possible to bear this cost for a family with low income. The Principal of the school mentioned that, as the school maintains ‘one teacher for one student policy’, it is the minimum cost needed to keep the teacher and other academic and non academic staff and the logistic supports to run the school activities smoothly. To minimize the financial burden, the school offers interested parents to become special educator by providing appropriate training and place them as teacher and also keep office staff from them. The school provides full free scholarship to one student from a very needy family. Without donation from government, non government, private or personal donation, it is impossible to minimize the school cost keeping the same quality of service.

Present Scenario of the School

SCSS is running successfully for the last eight years. The school is running its activities in two six storied buildings creating all indoor facilities needed for the students of different age group. In one building there are all girls student plus boys under 8 years of age. In the other building they have boys elder than 8 years of age and preschool children both boys and girls. Now the school has one hundred one students in two shifts, seventy six teachers and twelve office staff. From the very beginning the school follows ‘one teacher for one student policy’ to give best learning opportunity for the students. Whenever any student comes for admission, first task of the school authority is to assess the child. The school has expert special educator, psychotherapist, speech and language

therapist, occupational therapist for the overall assessment of the child. After initial assessment the child is placed to a shift as preferred by the parent. The school has three shifts for the academic activities; morning shift, day shift and full shift. Morning shift starts from 8.30 am and ends at 2.00 pm. Day shift starts from 2.30 pm and ends at 5.00 pm; and the full shift starts from 8.30 am and ends at 5.00 pm. The purpose of taking three shift are; some students are very young like three or four years old and are not used to stay at school for a longer duration, some high function students are able to go to regular school at the morning and they come to this school at day shift, most of the students come in the morning shift and some stays for full shift whose parents are working and who are teen aged and difficult to manage at home or don't have any caregiver to take care of the child during day time. Apart from these three shifts the school also has a preschool program for the students who have good academic learning ability and who have good achievements in speaking, reading, writing and communication skills. They are prepared in the preschool for sending them to normal school with other normal students and also provide shadow teacher for them if needed.

Regular Daily Activities of the School

After getting the admission in the school every single student is placed to a particular teacher who usually remains constant for that student and remains responsible for all daily activities and routine works with the student for certain period of time. The teacher is like a guiding angel for the student. For the first months the teacher is more like a observer, who observe all the activities of the child very closely and get to know about his/her behavior, attitudes, activities, likings or disliking, his/her fears or things that make his stressed, communication skills both verbal and non verbal, special abilities, daily life skills like dressing, personal hygiene maintenance, toileting, eating and drinking pattern etc. After month long observation the teacher submit his/her observation to the senior co-coordinator teacher and they also talk to the parents for the better understanding of the child's ability. Then they prepare the individual education plan (IEP) for that particular student. As every child with autism and other disabilities have many different characteristics and need, no uniform education plan works for all the students at the same time. That is why there is need for IEP. After developing the IEP; all daily activities with the student is guided by it. Daily routine activities of the school are; receiving the student by the teacher, greeting the student, asking about how he was at home, encouraging the child to communicate by himself, saying bye to the parents, changing the shoes, carrying his own school bag and going to the school room, changing the dresses, teeth brushing and refreshing, taking part in the morning assembly including national anthem, taking part in life skill training, regular exercise for

improving fine motor and gross motor skills, exercise for improving muscle power and coordination strength, routine physiotherapy, occupational therapy, speech and language therapy, psychotherapy, vocational training, computer training, routine table work, group work like group play, imitation, recitation of rhymes, saying prayers, taking breakfast and lunch with or without help, preparing the table for lunch etc. During the time of departure from the school the student greet the parents and say bye to the teacher and the teacher inform how he was doing in the class on that day.

Collaboration for Better Health Care Support and Social Inclusion

The school has developed collaboration with a nearby hospital and a diagnostic center for ensuring easy access to health care for the students. These are Farazy Hospital Limited & Farazy Dental Unit and Popular Diagnostic Center, Badda, Dhaka. Many of the students have health issues for which they need regular doctor's consultation and medications. These children are sometimes very hyper active and do not want to wait for a longer duration at the same place. So it becomes very difficult for the parents to wait for doctor's consultation for a long time. General people sometimes do not understand this situation and are not willing to give them priority. Sometimes the parents become very embarrassed while waiting for health care. These two organizations has visited the school and oriented with the special needs of these children in different meetings and workshops. They have agreed to provide health care to these students on a priority basis with less waiting time and less cost and signed a memorandum of understanding (MOU) with the school authority. As these children have a different social orientation, they feel more comfortable in their familiar environment like their home or school. Anything new whether it is a place or person gives them some kind of discomfort which in turn may make them hyperactive or non supportive. So, some of the health care procedure such as dental treatment, which takes a longer duration of time, may not be possible without extra care and technical skill. As these organizations are now committed to provide health care support to these students, they are orienting their staff accordingly so that they can handle them with better skill. Sometime the medical staffs come to the school for taking blood samples. Now the parents are happy to have easy access to health care for their special need children. This collaboration also increases the social awareness for children with autism and other disabilities. At first level it creates awareness among the staffs and through them to other people those who come for doctor's consultation, patients, their relatives or attendants. Awareness increases empathy and improves social inclusion of these special need children.

Dietary Advice by Expert Dietician

The children with autism and other disabilities are sometimes associated with some food allergies and need some restrictions of food. Maintaining age specific weight range and body mass index (BMI) is necessary to keep them active. Children with ADHD need to take less of those foods which make them more hyperactive. The school arranges dietary advice session for the students at the school premises with an expert dietician who has experience with the diet need of these special children. In our country taking dietary advice from the nutritionist is not very common except persons with severe diseases and referred by the medical consultants. For the children with autism and other disabilities taking dietary advice and practicing and managing the diet chart by the parents should be a regular practice. Diet advice session for the children with the parent and making the diet chart is a very good initiative. Follow up session and improvement of nutritional condition of the children should be regularly monitored for the betterment of these children.

Parent Teacher Association (PTA)

The school has recently developed a parent teacher association (PTA) with representative from the parents and teachers. The objective of this association is to monitor the needs and improvements of the children. If there is any dispute regarding any issues related to the children's health issue or teaching procedure or therapy session; the function of this association is to solve the dispute taking necessary action with the school authority. This association is helping the school management to improve the mutual understanding and dependence and reduce the conflicts and confusions. Being the parent of a special child is always very stressful and thoughts are always occupied with insecurity regarding the safety of the child and this PTA is reducing the stress of the parents and building a bonding and trust between the school authority and parents.

Special Initiatives

Daily routine activities of the school and therapies provided by the expert therapist the school has also initiated some special programs for exploring the hidden talents of the students. The school trains the students for cycling, swimming, special olympic athletic games, computer training, art and vocational training.

Conclusion

This school follows one teacher for one student methodology to develop the life skills and day to day activities of the children and provide regular occupational therapy, speech and language therapy, psychotherapy, vocational training, and music and dance therapy, teach cycling,

swimming and provide computer training. They conduct regular training session for the teachers and parents. They have developed collaboration with a nearby hospital that is committed to provide free health care support, doctor consultation, and dental care with minimum waiting time on priority basis. The school arranges regular nutritional assessment of these children with expert dietician. The school has also developed a parent teacher association to ensure the social support system for these special children. Besides the regular school activities, the integration of health care and social support is providing a positive thrust to the development of these children and improving their social acceptance.

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