

Experience of Parent's about Special Schooling of their Children with Autism Spectrum Disorder (ASD) in the Socioeconomic and Cultural Contexts of Bangladesh

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ABSTRACT

Autism Spectrum Disorder (ASD) has recently drawn much attention in Bangladesh. It is considered one of the most rapidly emerging developmental disorders. In Bangladesh, the educational infrastructure for children with ASD has expanded, but the quality and effectiveness of these services remain uncertain. The study explores the experiences of parents regarding the special schooling of their children with Autism Spectrum Disorder (ASD) within the socioeconomic and cultural contexts of Bangladesh. A qualitative research design was adopted, involving in-depth interviews with 22 parents from four special schools. Purposive sampling ensured diverse socioeconomic and cultural representation. The findings reveal significant gaps in facilities, communication, curriculum adaptation, and teacher training. This study offers recommendations for improving special education services in Bangladesh, highlighting the need for a comprehensive approach that includes parental involvement and policy support.

Keywords: Autism Spectrum Disorder, special education, special schooling, socioeconomic context, cultural context, parental experiences, Bangladesh, qualitative research.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex and increasingly prevalent developmental disorder that affects communication, behavior, and social interaction. Globally, the prevalence of ASD is estimated to be around 1 in 160 children, with a higher incidence reported in boys than in girls (Elsabbagh et al., 2012). In Bangladesh, the recognition of ASD as a significant public health issue has grown over the past decade, with estimates suggesting that approximately 1.4 million people may be affected by the disorder (Hossain et al., 2017). Despite this growing awareness, the provision of appropriate educational services for children with ASD remains a challenge.

Children with ASD usually demand a wide range of services, which are generally linked to health and educational needs (Lindly et al., 2019). As each autistic person is unique, each family's experience with autism will be different. Therefore, their services and education programs should differ according to their needs. The Bangladeshi government has made strides in addressing the needs of children with special needs, including those with ASD, through legislation such as the Disability Welfare Act (2001) and the Neurodevelopmental Disability Protection Trust Act (2013). However, the implementation of these policies at the school level is inconsistent, particularly in rural areas where resources are limited (Chowdhury et al.,

2014). Special schools, which are designed to cater to children with developmental disabilities, play a crucial role in providing education and therapy for children with ASD. Yet, the quality of these services and their impact on children's development remain under-researched.

Research conducted in other countries has shown that parental involvement in the education of children with ASD is a critical factor in their academic and social success (Dillenburger et al., 2012; Rattaz et al., 2014). Parents' perceptions of the adequacy of services provided by special schools can significantly influence their children's educational outcomes (Slade et al., 2018). However, in Bangladesh, there is a paucity of studies that explore the experiences of parents in this context.

This study aims to fill this gap by examining the experiences of parents whose children with ASD attend special schools in Bangladesh, with a focus on identifying the strengths and weaknesses of these institutions from the parental perspective. Open-ended questions asked parents to get detailed answers from them.

Research Questions

The main or general objective of this study is to investigate the experiences of parents of children with Autism Spectrum Disorder (ASD) regarding special schools in Bangladesh where their children study. The research questions are-

1. What types of special education services children with Autism Spectrum Disorder (ASD) are receiving from different special schools in Bangladesh?
2. How satisfied parents are with school services for their children with ASD?

LITERATURE REVIEW

The global prevalence of Autism Spectrum Disorder (ASD) has prompted extensive research into the educational needs of children with ASD and the role of specialized schools in meeting these needs. In Bangladesh ASD prevalence in rural areas was reported to be 0.75/per 1000 children (Akhter et al., 2018). Another study systematically reviewed six articles from three countries, Srilanka, India, and Bangladesh. This article reported that the prevalence of ASD is up to one in 93 children in the South Asia region. ASD prevalence in Bangladesh ranged from 0.15 to 0.8 percent. Prevalence was significantly greater (3%) in Dhaka, the capital of Bangladesh (Hossain et al., 2017). The Ministry of Social Welfare of Bangladesh reported that there may be as many as 1.4 million ASD sufferers nationwide (Chowdhury et al., 2014). International studies consistently highlight the importance of early intervention and tailored educational programs in improving outcomes for children with ASD (Posar & Visconti, 2017; Zablotsky et al., 2012). In the United States, for example, the implementation of Individualized Education Programs (IEPs) has been shown to enhance the academic and social development of children with ASD (Slade et al., 2018).

In developing countries like Bangladesh, the situation is more complex. The lack of resources, trained professionals, and awareness about ASD poses significant challenges to providing effective education for children with ASD (Bhuiyan et al., 2017). A study by Ehsan et al. (2018) revealed that many special schools in Bangladesh lack the infrastructure and skilled personnel necessary to support children with ASD, leading to dissatisfaction among parents. The literature on parental involvement in special education underscores the need for schools to engage parents as partners in the educational process (Leyser, 1985; Dillenburger et al., 2012). Parents of children with ASD often have unique insights into their children's needs and can provide valuable input into the development of educational strategies. However, research in Bangladesh indicates that communication between schools and parents is often inadequate, with parents feeling excluded from decision-making processes (Chowdhury et al., 2014).

Additionally, the curriculum used in many special schools in Bangladesh is not adequately adapted to the

specific learning needs of children with ASD. The use of standard primary school textbooks, as reported by parents, fails to address the unique cognitive and developmental challenges faced by these children (Hridi et al., 2020). International best practices suggest that curricula for children with ASD should be highly individualized, focusing on developing life skills, social communication, and sensory integration (Keenan et al., 2010).

Internationally many studies have examined various facets of parents' perceptions, the experiences of parents, and parent satisfaction with the education of their disabled children. In some earlier studies held in the twentieth century and later, although parents of children with ASD were included, studies were conducted in that the children had a range of disabilities, and the data was not broken down by disability category or specifically for autistic children (Parsons & Lewis, 2010). In the twenty-first century, some research explored parents, teachers, and health professional's experiences and opinions jointly on autistic kids' educational needs and services provided by special schools (Dillenburger et al., 2012; Saggars et al., 2019).

And in very few studies, the experiences and perceptions of parents of children with Autism spectrum disorders were specifically examined (al Jabery et al., 2014; Keenan et al., 2010; Rattaz et al., 2014; Renty&Roeyers, 2006; Slade et al., 2018; Zablotzky et al., 2012). Despite the passage of time and the fact that the research was conducted in various nations, the conclusions are remarkably similar. In recent studies, parents were asked to rate their overall experience with their children's education. The results show that while a slight majority of respondents are optimistic, many others are not. For instance, A qualitative study surveyed parents of 144 autistic children to learn about their opinions of and satisfaction with the education their children were receiving. Parents' dissatisfaction is greatly influenced by teachers' lack of knowledge of ASD's characteristics in that research (Starr et al, 2012).

Overall, the literature highlights significant gaps in the provision of special education services for children with ASD in Bangladesh. While there is growing awareness of the need for specialized education, there remains a disconnection between policy intentions and actual practice at the school level. This study seeks to contribute to the existing body of knowledge by providing a detailed examination of parental experiences with special schools in Bangladesh, identifying areas for improvement, and suggesting policy interventions.

METHODOLOGY

This study employs a qualitative research design to explore the experiences of parents regarding the special schooling of their children with Autism Spectrum Disorder (ASD) in Bangladesh. The research design was chosen to allow an in-depth understanding of the complex socioeconomic and cultural factors influencing parental experiences. The study was conducted in the Rajshahi division, where four special schools were selected based on accessibility and willingness to participate.

A purposive sampling method was employed to select 22 parents who represented a diverse range of socioeconomic backgrounds. This approach ensured that the study captured a broad spectrum of experiences, reflecting the varying conditions in which special education is provided in Bangladesh. Data were collected through semi-structured interviews, which allowed for flexibility in probing deeper into the parents' experiences and perspectives.

Thematic analysis, as outlined by Braun and Clarke (2012), was used to analyze the interview data. This method involves identifying recurring themes and patterns within the data, which are then organized into meaningful categories. The analysis focused on understanding the specific challenges faced by parents, the effectiveness of the services provided by special schools, and the areas where improvements are needed.

Ethical approval was obtained from the relevant institutional review board. Participants were informed

about the purpose of the study, and their consent was obtained before data collection. The confidentiality of the participants was maintained throughout the research process.

FINDINGS

The analysis of interview data revealed seven major themes that encapsulate the experiences of parents regarding special schools for their children with ASD in Bangladesh:

1. Facilities and Services are Insufficient

Many parents expressed dissatisfaction with the facilities and services provided by special schools. There are only some facilities and services available for children with ASD.

Autistic children are special, for them, life-living skills are more important than academic excellence. Parents discussed facilities their children get from the school for developing life skills like Self-help skills, Social skills, Fine motor and, Gross motor skills of children. Most of the parents of children with ASD mentioned some common types of services they received from the different special schools. Occupational Therapy and Speech Therapy are two most common types of therapies that they get from special schools. Most of the comments from parents were negative against the facilities and services they get from special schools.

One parent illustrated that,

The school doesn't teach any kind of self-help skill, my child is still dependent on me, even though the school doesn't have proper toilet facilities in the school.

Another parent told the same thing,

School tries to teach some self-help skills like how to tie the laces of shoes, and button up the shirt but these are less important skills. The most important thing is the regular activity that the school doesn't teach.

Another said,

It's been 8 years since my child is here. During these years my child was promoted only in 3 classes. He still can't do anything. Dependent on me at home, I wish he could at least learn from school how to take care of himself.

When the researcher asked the parents to elaborate on what she meant by important regular activity then she mentioned: *Eating properly, Brushing, Bathing, Toileting, etc.*

Parents had given negative information about the therapy and educational services provided by special schools.

A parent expressed her rage that,

Before admitting my child we were informed by the school authority that, this school provides many essential therapies for Autistic children. The school still claims that they provide occupational therapy and speech therapy. But the quality of the therapy is so poor that, I take my children to a private occupational therapy center regularly according to the suggestion of my child's doctor.

Parents also mentioned the unavailability and insufficiency of vocational education. 16 out of 20 parents shared there is no vocational education and training available in this school. Parents from only one school

mentioned that there is vocational education in their school but that service is not suitable for their child.

In her words,

Though the school has a vocational program, they teach computers but I don't think my child could learn anything from there because, he is not able to learn computer.

Contrary to the above comment some parents also shared some positive statements regarding the school's services and facilities. 70% of them appreciate the extra-curriculum activities of special schools. Schools provide extra-curricular activities for improving children's social skills, fine motor, and gross motor skills.

Parents mentioned,

For developing fine motor and gross motor skills teachers play various kinds of games inside and outside of the classroom. Like as; Playing football and handball, throwing and catching balls, throwing the ball into the basket, making handcraft with paper, and making jewelry with thread and beads.

One parent expresses her feeling that,

The school serves very good extra curriculum activities. My child is doing well in the drawing. He got a district-level award in the drawing.

Another parent informed that,

My child is very good at dancing, the school organizes cultural programs on different special days and the children perform well.

Another said,

My child is very good at sports, school gives us hope that they will prepare my child for attending the Special Olympic game.

2. No Special Textbooks and Teaching Methods for Children with ASD

Academic skills are very important for any student. Because, normally a school's success is measured by its academic success. But children with Autism spectrum disorder are special students. There should be a special curriculum, textbook and special teaching techniques and methods for educating these children according to their learning needs.

When parents were asked about the types of services they get from the school for their child's academic development parents mentioned some teaching techniques and methods the school follows for teaching their children. Although, during the interviews, most of the respondents indicated that there are no special textbooks in the school.

One parent mentioned,

The school doesn't have any special textbook for teaching her autistic child. Though, they try to use many techniques for teaching, like they sing rhymes, playing with the child, and using some playing materials.

All most all of the parents noted that schools use normal primary school textbooks for teaching academic skills to children with an autism spectrum disorder.

A parent described that,

School teaches normal academic skills to our children like reading, writing, numbers, and calculations. For this, they use primary school textbooks, and teachers also give homework work to our children.

Corresponding another parent said,

The school uses normal textbooks that are used in normal primary school for teaching our children. And what they do in the classroom is common in any kindergarten school in the city. Nothing is special.

Parents also identified that the school integrated all types of special children into the same class. And the school also don't separate students' class according to their age and degree of disability. This is a big issue because they use the same curriculum and education programs for all types of special needs students without considering their educational needs.

A respondent expresses her feelings that,

The school I have admitted my child to is a special school for special children. But they teach all types of special students in the same class. Like, there are Down syndrome and mentally retarded children who are also in the same class with my autistic child.

3. The Level of Communication with Parents is Insufficient

The school serves a very poor level of communication services according to the parent's opinion. 65% of parents stated that they have no idea what their child learns in school. Schools never communicate with parents and get them informed about what is going on at school. Most of the parents mentioned, they eagerly communicate with the schools to know about their children's education and progress.

One parent said,

Most of the time I eagerly communicate with my child's class teacher about her progress. But from school, they never communicate with me first. They only communicate when it's about paying school fees or any other upcoming occasion. They call us on our number or send us a letter in our child's school bag.

Another parent said,

I come to school regularly with my child. I stay here all the time as long as my child is in the classroom. I wait outside in the class. Sometimes the class teacher communicates with me. If my child makes any mess in the classroom, or If he can't handle my child in the classroom. Then he asked for my help.

Most of the parents informed that the school doesn't arrange any parent meetings or they have never been invited to such kind of meeting ever. 35% parents mentioned that schools hardly arrange parent meetings.

One parent shared that,

Before corona pandemic, the school used to organize parent meetings every month, but after the pandemic is over there are no parents meeting they invited me to attend.

On the contradictory another said,

This school held parent meetings hardly and they (Teachers) express their opinion regarding our children's education, they also listen to our suggestions but we don't see the actual work (implementation) of our suggestions.

Another parent shared that,

They (The school authority) sometimes send parents' meeting invitation letters inside my child's school bag. It was unexpected that in this digital era they don't call me or send me a text on my phone but send me letters.

4. Parent's Involvement in IEP is Absence

IEP or Individual education program is one of the very important components for educating children with an autism spectrum disorder. Where all the information of a child is kept recorded and a guideline is planned as to how all the processes and procedures of educating a child will go on. When Parents of children with autism spectrum disorder were asked about their child's education program, Different data come out regarding this. Most of the parents answered that they have no idea about IEP. Some parents said that there is no such thing in their school.

One parent answered

There is no individual program for any children. They teach all the students in the same way and use the same techniques for everyone.

Another parent said,

I have heard about the individual curriculum program for disabled children but I don't think these types of advanced teaching methods exist in this village school, because the school never informed me about anything like this.

According to 25%parents' opinions, there is IEP in their children's schools. But the school authority doesn't update the IEP on the regular basis and doesn't involve parents in it

A Parent informed that,

When I admitted my child for the first time in this school, they asked me a lot of information regarding my child, such as: what the doctor told me about my child, how much affected he is by autism, whether can he talk, and how he responds. They told me that they will use this information for making an education program for my child, but it had been 3 years since my son studied here they never again asked for any information from me about my son.

Another parent expressed her experience,

Teachers don't like to take any ideas from me on how to teach my child. Whenever I tried to give them any suggestions they discouraged me. They never allowed me to let them give good suggestions on how to teach my autistic child.

5. Trained Teacher and Specialist Needed

During the interviews, different responses emerged, which indicated that there is a lack of trained teachers and specialists in special schools for children with autism. All participants shared the same experience about the lack of trained teachers and specialists. They urged that teachers of the special school need more

education and training regarding teaching their children with autism.

Around 70% of parents mentioned,

The school doesn't have any expert teachers or specialists. There is no trained occupational therapist or speech therapist.

Similarly, one parent specifically mentioned that,

The school hired a speech therapist sometimes. There is no permanent therapist.

All of the parents noted that there is no psychologist in the school where they admitted their children with an autism spectrum disorder.

Parents from a city area school echoed the same sentiment,

There is no psychologist in this school who counsels us (parents) or our children.

Most of the parents shared the lack of trained teachers in the school to educate and handle their children properly in the school.

A parent expressed,

The teachers are inexpert about the fact of managing the behavior of students. They always need our (parents') help. I mean the help of mothers who attended school with their children. I hope the teacher would be sincere and more caring for my child.

Another described,

Schools should involve more teachers or "supporting teachers" in the classroom because they always need parents' help to manage their children.

Another parent articulated that,

I wish the teachers of the school are more experts to handle my child alone without my help, then I would not need to attend school with my child every day. I could spend my time on my other personal work.

In a special school, all the children studying are special. Teachers should have well knowledge about them and should be trained first before joining this profession. Some parents shared their stories which revealed that teachers of the special schools are not properly trained.

One parent described,

Once my child got so excited and was showing anxiety, he started shouting and crying then the teacher alone could not control him, I came over to the classroom to help her and I had to take my child home

One more parent shared her story,

Once, my child was so excited in the classroom, he was shouting inside the class. But I was astonished that the teacher was shouting back at my child. I don't think this is the proper way to handle an autistic child. I had given a complaint against that teacher to the head teacher.

Another parent recommended,

Teachers should train every year to give them updated knowledge so that they can serve updated education to our children. I want a fully trained expert teacher for my children.

A parent also expresses her positive feelings that,

I think the teachers are very attentive and they try to do their level best. They are willing to support the learners. But they are not getting enough support from higher authorities. Government should arrange education and training programs for the teacher and make them experts in this field.

6. Problems in Transportation Service

Transportation is one of the most important support services for children with ASD. Children with ASD for their accessibility to the special school may need transport services from the school. Some participants stated that there is no transportation service in the school.

According to one parent,

The school doesn't have any transportation services. We take him to school every day or sometimes we let him go alone. But we feel insecure when he goes to school alone.

All of the parents stated that there is a transportation service in the school. Most of the schools have vans for transport students from home to school and school to home, though parents are not fully satisfied with the service.

As one parent described,

The school has a school van to carry children from home to school. But the transportation service is only for the students whose homes are nearer to school. Our home is 20 kilometers away from school. And the school van doesn't come here to take my child. I have to take him to school by myself, so the transportation cost every day is a burden for a low-income family like us.

Another parent emphasized the same matter,

The school fees are okay for them but for transportation, they spend 3000 to 3500 taka per month, and it's not easy for us.

Students with autism spectrum disorder always need special care in every aspect of their education program and their regular life. In transportation services, they also need special take care, which is not currently available in most special schools.

As one of the parents highlighted,

The school serves transportation services. The school-van comes across our home every day. But as our son has social anxiety he doesn't like to go to school by school van. He always wants me to take him to school. But the school van carries the students only not their parents. For this matter, we have to spend extra money on transportation costs.

7. Other Recommended Services from Parents

When parents of children with autism spectrum disorder asked about what other facilities and educational

services they expect from the school then parents expressed their expectations and recommendations. 8 parents directly asked for parent training from the school.

One parent said

I didn't get any training from school, on how to take care of my child at home, it would be better if the school provide training for parents.

Another parent said,

A couple of years ago one day the school selected some parents of autistic children and took them for training. That one-day training was great. I learned a lot from that training. I wish these types of training programs were held more for parents of autistic children.

Social-skills teaching was also frequently noted by parents as a crucial requirement for the education of their children. Some parents also hope for their children that one day they will live a normal life like normal people

A parent emphasizes that,

I want my child to at least to learn social communication and understand real life.

One parent stated that,

We don't bother if he does not manage to get an education fully. All I want is for him to survive in the society

Regardless of a child's condition, all parents have similar hopes and expectations for their children. Almost all parents want their children to live happily and independently in the future.

One parent expected that,

I expect the school to teach him employment skills and the in future manage any kind of employment for my child so that he could be financially independent.

Another parent said,

It's been a year since my child was admitted here. But still, he doesn't even communicate properly. I am very concerned about his future. What will he do in the future? I wish the school could have taken some steps to make my child's future secure.

Another parent said,

I need financial support from the school and the government to make a secure future for my children.

The next most highly referenced needs were the use of more technology.

A parent illustrated,

School resources are limited. Educators do not have enough resources to help the learners. They don't use any practical objects or information technology, like showing videos or pictures while teaching the students.

Another parent explains that,

The school always teaches my children in the same old way, it has been 6 years my children studying here and there is nothing new. The school should adopt new methods and technologies that are going on outside

in Developed countries.

Researchers examine empirical information related to special education for children with ASD. The researcher attempted to portray an actual situation of the special education system for children with ASD in the context of Bangladesh from the parent's point of view. All the respondents' responses have not been used in this analysis but maximum relevant arguments have been used.

DISCUSSION

The findings of this study highlight significant gaps in the provision of special education services for children with ASD in Bangladesh. The lack of specialized curricula, insufficient communication with parents, and the absence of trained professionals are critical issues that need to be addressed to improve the quality of education for these children. These findings are consistent with international research, which underscores the importance of tailored educational programs and parental involvement in achieving positive outcomes for children with ASD (Dillenburger et al., 2012; Slade et al., 2018).

The study also highlights the importance of parental involvement in the education process. Parents are key stakeholders in their children's education, and their experiences and insights are invaluable in shaping effective educational strategies. Schools need to establish better communication channels with parents and involve them in the planning and implementation of individualized education programs.

Furthermore, the findings suggest that there is a need for policy-level interventions to ensure that special schools are equipped with the necessary resources and trained personnel to provide quality education to children with ASD. This includes the development of a standardized curriculum tailored to the needs of children with ASD and the provision of ongoing professional development for teachers and specialists.

CONCLUSION

This study has provided an in-depth examination of the experiences of parents whose children with Autism Spectrum Disorder (ASD) attend special schools in Bangladesh. The findings reveal significant gaps in the quality and effectiveness of the services provided by these institutions. The lack of specialized curricula, insufficient communication between schools and parents, inadequate facilities, and the need for more trained professionals are major challenges that hinder the educational development of children with ASD.

Addressing these issues requires a multifaceted approach that includes policy interventions, resource allocation, and capacity building within special schools. It is essential to develop and implement Individualized Education Programs (IEPs) that cater to the specific needs of children with ASD, and to ensure that teachers and specialists receive ongoing training in the latest educational techniques and therapeutic practices. Furthermore, improving communication with parents and involving them in the educational planning process can enhance the overall effectiveness of special education services.

The insights gained from this study can guide educators, policymakers, and practitioners in their efforts to improve special education services in Bangladesh. Future research should focus on evaluating the long-term outcomes of educational interventions for children with ASD and exploring the potential for integrating technology and innovative teaching methods into the classroom. By addressing these challenges, we can work towards creating an inclusive and supportive educational environment that enables children with ASD to reach their full potential.

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