

Barriers in Access to Regular Schools for Children with Autism Spectrum Disorder in Odisha: A Caregiver Perspective based Qualitative Research

Sunanda Banerjee¹, Tazyeen Arifa², Dr. Jigyansa Pattnaik³

¹Kalinga Institute of Medical Sciences, Bhubaneswar, Odisha, India
Email: sunandabanerjee928[at]gmail.com

²Kalinga Institute of Medical Sciences, Bhubaneswar, Odisha, India
Email: tazyeenarifa116[at]gmail.com

³MBBS, MD, DNB, PDF (Child Psychiatry) Assistant Professor, Department of Psychiatry, Kalinga Institute of Medical Sciences (KIMS), KIIT University, Bhubaneswar, Odisha, India
Email: drjigyansaipsita[at]gmail.com

Abstract: *This article explores the challenges and barriers faced by children with Autism Spectrum Disorder ASD in gaining access to regular school education in India. It highlights the importance of early diagnosis for effective interventions and emphasizes the need for inclusive education to accommodate children with ASD and other developmental setbacks. The study conducted interviews with 8 parents of children with ASD to understand their perceptions and experiences. The findings reveal the lack of awareness about inclusive education, stigmas, and infrastructure issues that hinder the inclusion of children with ASD in mainstream schools. The study advocates for a societal shift towards inclusive education to ensure the fundamental educational rights of intellectually atypical children.*

Keywords: Autism Spectrum Disorder, inclusive education, barriers, parental perception, qualitative study

1. Introduction

Autism comes under the umbrella of a type of neurodevelopmental disorders called pervasive developmental disorders (PDD). These disorders are usually characterized by three main core deficits including: impaired communication, disabled reciprocal social interaction, and restricted, repetitive and stereotyped patterns of behaviours or interests. The presentation of such impairments varies in range and severity. They often change when the child acquires other developmental skills. ^[1]

Worldwide, Autism spectrum disorder (ASD) is one of the major causes of disability during childhood. In India, it is calculated that approximately 1.7–2 million children are afflicted with this disorder. To start early interventions, early diagnosis is an important criteria for ASD treatment. However, for each and every childhood disability which receives a medical diagnosis, there is usually a period between parents' first realization of atypical symptoms and the eventual medical diagnosis. ^[2]

Considering the rising number of children diagnosed with ASD, school systems need evidence-based, efficient and cost-effective educational models that approach the rigorous, specialized and intensive learning requirements of students with ASD, as well as the essential needs of the teachers. ^[3] Most students with ASD and other disabilities (76%) are still put in 'special' (segregated) education schools, but there are certain indications of movement towards inclusion in the future.

Students with special educational requirements are often discouraged from being admitted to mainstream schools. These special schools increasingly attract children with

multiple disabilities; and the fear for change makes special school educators unwilling to promote inclusion. Some parents have a tendency to try to 'normalize' their impaired child by their admission to mainstream school attendance, where they are not able to meet their complex individual requirements. Frequently, there is insufficient acceptance of the need for intensive measures to ensure and promote social and educational inclusion. This can be particularly of supreme importance and highly difficult for the autistic students. Consequently, there is an immediate need to implement well-resourced mainstream education for every child, irrespective of their developmental setbacks. ^[4]

The Indian Government's program of Universal Elementary Education (also known as Sarva Shiksha Abhiyan) for every child up to the age of 14 cannot be implemented efficiently without including CWSN in the education system of our schools. Inclusive education essentially highlights an educational system which is capable of accommodating all children despite their physical, social, emotional, intellectual, linguistic, or other existing limitations. It is essential to include CWSN (especially the students with ASD) in the educational system of any country, for the required development of social skills and subsequently, better social interaction. Today, the scenario of special education progresses towards improvement, with a large number of children with autism being identified and obtaining special educational services. ^[5]

Lack of trained educators, ill-maintained infrastructure and stigmas experienced at schools; lack of inclusive educational curriculum and the given atmosphere has a direct association with the fact that only a handful of children with intellectual impairments get admitted to the mainstream schools. The awareness about inclusive education is still in its infancy

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throughout the country. In reality, special education is given a higher position in the case of children with intellectual impairment. However, this outlook is depriving the larger population of such students of their fundamental educational rights. It is of utmost importance to stimulate a change in our society by adopting the methods of inclusive education to promote the equity of intellectually atypical children and provide them with the fundamental educational rights which were guaranteed to them by our constitution. ^[6]

The present study attempts to decipher the parents' or caregivers' perception regarding ASD and to understand the barriers experienced by the children while gaining access to regular school education.

2. Materials and Methods

The study followed a qualitative approach to understand the parents' or caregivers' perception regarding ASD and to approach the barriers experienced by the children while gaining access to regular school education.

Institution Ethics Committee approval was obtained in October 2022 for a study on barriers in access to regular schools for children with autistic spectrum disorder from a caregiver's perspective in Odisha. In this study, we interviewed 8 parents with a child having autistic spectrum disorder in the outpatient department. Data saturation was achieved at 6 and 2 more were done to confirm the same. Nonrandomized, purposive sampling was used to recruit participants for the study. The following were the inclusion criteria: Parents of children with Diagnosis of Autism Spectrum Disorder- (as per DSM-5) and within the age group of 3-12 years and those willing to consent. Exclusion criteria included those with Intellectual Developmental disorder (DSM-5), Cerebral Palsy, Congenital Metabolic/genetic disorders. The participants provided oral consent at the start of the interview. Data was collected through individual in-depth interactive sessions with 8 parents from March to June. Interviews were carried out by a senior psychiatrist who had experience in qualitative studies. Her experience may have influenced the way in which she related to the participants and interviews were conducted. The identities of all individuals were masked to maintain confidentiality and anonymity. The length of the interview ranged from 30-45 minutes.

Sub-Theme	Quotes
1. Fear of the teachers	<p>"He started hitting his head multiple times in class suddenly, which frightened the teacher. She asked me to take him back home. Since then, he has not gone back to school."</p> <p>"He is hyperactive and does not understand anything. He keeps talking to himself, and never pays attention to anything else. That is why we fear that he will injure someone in school due to his hyperactivity. He will be sent back home, and the teacher will not know what to do."</p>
2. Lack of knowledge of inclusive education	<p>"She makes him sit in the corner of the class in isolation such that his hyperactivity does not disturb the other students of the class."</p> <p>"She is a regular at school, and she has made a few friends. She studies with everyone in her class. However, the teacher complains that she is not studying at all. She goes to tuition, and attends classes regularly in school. But her results are not satisfactory for her teachers."</p>

2) Concerns about Hyperactivity and Behavioural Challenges:

Several caregivers expressed concerns about their children's hyperactivity and behavioural challenges affecting their ability to attend regular schools. They are mostly too afraid

The interviews were transcribed verbatim immediately after the interview. Various triangulation methods were used, and a phenomenological approach was used for the study. Major themes and sub-themes recognized were used for further qualitative analysis.

3. Results

The sample consisted of 8 participants, out of which 6 were male and 2 were female. The demographics of the sample are presented in the following table:

S. No.	Gender	Age	ISAA Score	Associated Diagnosis
1	Male	5	81	None
2	Male	3	97	None
3	Male	16	91	None
4	Female	8	101	ADHD, IDD
5	Male	5	126	ADHD
6	Male	7	92	None
7	Female	6	79	ADHD
8	Male	5	77	ADHD

The Qualitative summary of the In-depth Interviews is described below:

1) Negative Attitudes of the Teachers:

The interview of some caregivers highlighted that teachers' attitude towards the children with ASD had a major impact on sending their child to school. The negligence and ill-behaviour towards ASD children by the teachers has been a major contributor to their inaccessibility to regular schools. The sub-themes are:

- Fear of the teachers: Some of the caregivers mentioned that the teacher asked them to take their child back home because he was displaying violent behaviour. The teacher had misinterpreted the child's hyperactivity for self harm, which frightened her. For the sake of other students' safety, the ASD child was asked to be removed from school by the teacher to the caregivers.
- Lack of knowledge of inclusive education: The caregivers mentioned that their child was usually made to sit in a separate spot, isolated from other students such that they are not disturbed during classes. This showcases their lack of approach towards inclusive education and a hindrance to the child's education.

to send their children to regular schools as they think they might harm others or themselves, or the teachers might send them back because of their behaviour. The sub-themes are:

- Fear of self-harm and harm to others: A few caregivers had the perspective that their child's hyperactive

behaviour might harm the other students, and themselves, during school hours. That is why they were unwilling to send them to school.

- Fear of lack of support from teachers: The caregivers believed that the behaviour portrayed by their children in

regular schools might frighten and annoy the teachers, hence leading to sending their children back home. Such misconceptions can lead to a major barrier in children's education.

Sub-Themes	Quotes
1. Fear of self-harm and harm to others	“He is hyperactive and does not understand anything. He keeps talking to himself, and never pays attention to anything else. That is why we fear that he will injure someone in school due to his hyperactivity.” “At school, he does not display any symptoms of hyperactivity, and thus the teachers have no complaints.”
2. Fear of lack of support from teachers	“He is hyperactive and does not understand anything. He will be sent back home, and the teacher will not know what to do.”

3) Communication and Understanding Difficulties:

Caregivers mentioned challenges in communication and understanding their children with ASD. It is easier for them to let their child sit alone and play with their electronic devices rather than trying to sit and understand them. This led them to believe that the teachers at regular schools would have a difficult time understanding their child, hence not sending them to school at all. The sub-themes would be:

- Failure to communicate: Some caregivers fail to have a proper channel of communication with their children as they do not understand their child's social barrier. It is easier for them to keep their child engaged with electronic devices rather than understanding how to communicate with them.

- No provision of special attention: The caregivers think that their child's behaviour would not be perceived by the teachers in a positive manner, which would lead to sending their child back home by the school authorities. Thus, they do not send their child to school and do not provide them with special attention and care in terms of education.
- Barrier of Hyperactivity: The hyperactive nature of their children makes it difficult for the caregivers to interact with them. Hence, they think that the teachers will have a difficult time grasping this behaviour, thereby not sending them to school at all.

Sub-Themes	Quotes
1. Failure to communicate	“He is hyperactive and does not understand anything. He keeps talking to himself, and never pays attention to anything else.” “He understands a few words here and there. We cannot talk to him normally. I suppose the people in school will have a hard time understanding him.”
2. No provision of special attention	“We fear that he will injure someone in school due to his hyperactivity. He will be sent back home, and the teacher will not know what to do.”
3. Barrier of Hyperactivity	“We have tried to take her to school. But she never goes beyond the gate. We have tried to drag her inside, but she never wants to enter the school premises.” “We fear that he will injure someone in school due to his hyperactivity. He will be sent back home, and the teacher will not know what to do.” “At school, he does not display any symptoms of hyperactivity, and thus the teachers have no complaints.”

4) Lack of Inclusive Education:

There is a potential lack of inclusive practices in regular schools which provides an environment to accommodate the specific needs of children with ASD. A few caregivers mentioned that their child's poor performance in school led to a series of complaints from the teachers. Some caregivers feared sending their child to regular schools as they thought that their behavior would not be accepted by the authorities. Additionally, the absence of private tutors or alternative educational options indicates limited access to education for the children with ASD. The sub-themes are:

- Lack of an inclusive environment in regular schools: Some of the caregivers mentioned that their child was unwilling to enter the school premises, despite dragging them inside. This highlights the lack of inclusivity and proper accommodation for children with ASD in regular schools.
- Lack of special educators: Most of the caregivers stated that their children's schools did not have provision for special educators and one on one teaching methods for their children. This creates a huge barrier to the education of children with ASD.

Sub-Themes	Quotes
1. Lack of an inclusive environment in regular schools	“She makes him sit in the corner of the class in isolation such that his hyperactivity does not disturb the other students of the class.” “We have tried to take her to school. But she never goes beyond the gate. We have tried to drag her inside, but she never wants to enter the school premises.” “She is a regular at school, and she has made a few friends. She studies with everyone in her class. However, the teacher complains that she is not studying at all. She goes to tuition, and attends classes regularly in school. But her results are not satisfactory for her teachers.”
2. Lack of special educators	“Manas started hitting his head multiple times in class suddenly, which frightened the teacher. She asked me to take Manas back home. Since then, he has not gone back to school.” “His teachers are supportive, they try to provide him adequate education even with his condition.”

5) Varied Teacher Support and Special Education:

The level of support and access to special education services varied among the interviewed caregivers. Some parents addressed the fact that the teachers were supportive and the availability of a private special educator for the child. In contrast, a few caregivers mentioned concerns from the teacher about the child's lack of academic progress despite regular attendance. The sub-themes are:

- Provision of special education: Some caregivers stated that their children were provided with proper attention and special educators in schools if required. This highlights a positive shift of the regular schools towards inclusive education.

- Dissatisfaction of teachers with their academic performances: Many parents mentioned that the teachers complained that their children's academic performance was not up to the mark. This showcases a lack of special academic provisions for the children with ASD at regular schools.
- Lack of proper training of teachers: The teachers were unaware of the appropriate methods to communicate with the children with ASD. One of the child's teachers sent him back home because of his hyperactive behaviour. This demonstrates a lack of knowledge and training of the teachers at regular schools.

Sub-Themes	Quotes
1. Provision of special education	"If the school thinks that she requires special care, special educators are provided to her directly from the school. They help her learn better." "His teachers are supportive, they try to provide him adequate education even with his condition. We have hired a private special educator for his studies, such that he gets the best out of his education. He recently cleared class 8 with average marks."
2. Dissatisfaction of teachers with their academic performances	"She is a regular at school, and she has made a few friends. She studies with everyone in her class. However, the teacher complains that she is not studying at all. She goes to tuition, and attends classes regularly in school. But her results are not satisfactory for her teachers."
3. Lack of proper training of teachers	"Manas started hitting his head multiple times in class suddenly, which frightened the teacher. She asked me to take Manas back home. Since then, he has not gone back to school." "She makes him sit in the corner of the class in isolation such that his hyperactivity does not disturb the other students of the class."

6) Impact of Therapy and Symptom Resurfacing:

The caregivers discussed their child's positive experience at school while receiving therapy. However, after stopping therapy, the child's hyperactivity symptoms resurfaced, leading to the decision to seek professional help. This suggests that ongoing therapeutic interventions may play a role in facilitating access to education for children with ASD. The sub-themes are:

- Effect of therapy: Most caregivers mentioned that their children had a major improvement in terms of symptoms after interventional therapies such as behavioural and speech. Hence, regular schools became more accessible to these children.
- Stoppage of therapy: A few parents stated that after stoppage of therapy, the symptoms of hyperactivity resurfaced. This led to certain academic and behavioural setbacks in school.

Sub-Themes	Quotes
1. Effect of therapy	"He has been going to school. At school, he does not display any symptoms of hyperactivity, and thus the teachers have no complaints. After the intervention of speech therapy and behavioural therapy, he has been studying, doing his homework, and concentrating on his class work." "When it comes to school work, she has been doing it quite well. After the intervention of speech therapy and behavioural therapy, she has been performing well at school. She works with her peers, studies well, and does her homework. The teachers have no complaints. She has been doing great."
2. Stoppage of therapy	"When she was receiving therapy, no one could tell that she was autistic. The teachers could not identify her condition as she behaved like a normal child. She had made a lot of friends in school, studying well and performing her daily activities quite effectively. We decided to stop the therapy after that. Since the last 5 days, her symptoms of hyperactivity have resurfaced."

4. Discussion

This study helps us understand the barriers encountered by autistic children through the perspective of their caregivers. It enlightens us to promote the concept of inclusive education, which includes active involvement of typically developing, inclusive social activities, and equal opportunities for autistic students to have an equal share of roles and responsibilities. The following themes emerged: negative attitudes of the teachers, concerns about hyperactivity and behavioural challenges, communication and understanding difficulties, lack of inclusive education, varied teacher support and special education, and impact of therapy and symptoms resurfacing.

These interviews gave an insight to the struggles faced by the caregivers for providing quality education to their children with ASD. Highlighting the first theme, most of the mainstream school teachers are not trained enough to interact and guide the children with ASD. This lack of training leads to a huge communication gap between the teacher and the student. It was noted that these teachers had unrealistic academic expectations from these children. This showcases the lack of knowledge regarding ASD amongst school teachers. These scenarios advocate for better training of mainstream school teachers, implementing the features of special education in such schools and also the creation of a safe and secure environment within the school premises for the autistic children.

This study shows that parents play an important role in the provision of education to their autistic children. Behavioural concerns and communication difficulties prevent them from sending their children to mainstream schools. The hyperactive behaviour of autistic children also creates a major barrier to their education, as the parents find it difficult to cope with it. Most parents struggle to understand and comprehend the behaviour of their children. This highlights the need for more advocacy about autism, especially informing the parents about inclusive education and the implementation of socially secure measures for their child.

Few interviews stated that special educators provided to their children had a major role in establishing adequate academic standards for them. It helped them to learn better, and made it easier to approach the classes in school. This indicates that one on one education is an essentiality for the autistic children, and all mainstream schools must provide special educators to these students. Lack of trained personnel is a huge hindrance to the provision of quality academic needs for the children with ASD.

This study also implicates the initiation of effective policy making in Odisha to build adequately funded schools, and sufficiently high-quality resources to support superior quality teaching for the atypical children. The Sarva Shiksha Abhiyan program advocates the admission of these children in mainstream schools, however, multiple barriers continue to limit its full utilization.

The temperamental characteristics of these children could also be a reason for exclusion from mainstream schools, and it could be incredibly challenging to the already overburdened teacher at mainstream schools with the grossly inadequate teacher to pupil ratio. Even in special schools, teachers find behavioural problems, temper tantrums, and attention deficit among these children quite challenging to manage and can considerably take up the entire teaching hours. According to Charman et al, emotional, conduct and hyperactivity problems were found to be higher in children with language impairment and ASD recruited from mainstream schools. The classroom atmosphere should be conducive to children with sensory sensitivities, and their peers should be supportive and compassionate towards them. In conclusion, parental attitude, lack of adequate resource personnel, and curriculum tailored to their needs are likely impediments for effective inclusion.

Limitation

The major limitation of our study was the inclusion of caregivers of only children with ASD. Other children who require special educators (for example, children with Intellectual Developmental disorder (DSM-5), Cerebral Palsy, Congenital Metabolic/ genetic disorders, etc) were excluded from the study. This must be addressed in future studies.

5. Conclusion

The above study brings forward the various challenges experienced by the caregivers of children with ASD in light of inclusive education. Further studies might be needed to look at the reasons for this trend and to address them

effectively, so that inclusive education becomes a reality rather than an enigma.

Key Messages

Behavioural problems and communication barriers were some of the common problems faced by educators in special schools and addressing them is essential to prevent adverse learning outcomes. Parental attitude, lack of adequate resource personnel, and curriculum tailored to their needs are likely impediments for effective inclusion. Such barriers must be addressed, and improvement strategies should be implemented to provide the best quality education for the children with ASD.

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Conflicts of interest

There are no conflicts of interest.

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Author Profile



Sunanda Banerjee is a third year MBBS student at Kalinga Institute of Medical Sciences, Bhubaneswar. She is passionate about medical research and aims to expand the reach of medical research in the Indian education system. She has been a part of multiple international conferences and exchange programmes across the world.



Tazyeen Arifa is a third year MBBS student at Kalinga Institute of Medical Sciences, Bhubaneswar with a keen interest in research and its application in the field of medicine. She is passionate about contributing meaningfully to advancement of medical science and patient care.