

INCLUSIVE EDUCATIONAL BARRIERS IN AUTISM: A PARENTAL PERSPECTIVE IN KERALA

Aim: Autism is increasing at an alarming rate, internationally it is 1 in 66. Autism is a complex bio-neurological disability. Children with autism spectrum disorder (ASD) are challenged by the most essential human behaviours. Autism is characterized by impaired social interaction and communication, and by restricted and repetitive behavior. Inclusive education for special children opened a new era in the current educational scenario. However, limited research depicts the pros and cons of inclusive education. In the light of this, the study implies the stumbling blocks in the journey of inclusive education for children with autism through the eyes of a parent.

Method: The paper is based on qualitative study with seven parents having children with autism selected from three special schools in Ernakulam district, Kerala. In sampling procedure, purposive sampling is adopted for the study since it's a qualitative study and primary data is collected from parents through semi-structured interview while, the secondary data from books and journals. Primary data was coded and four themes were emerged through data analysis.

Results: This qualitative study explored the parent's perception on inclusive education through a variety of experiences they had with mainstreaming their children through the inclusive educational system. Four relevant themes emerged through this study includes, attitude and knowledge of teachers, school climate and social isolation. Findings highlighted the significance of developing certain strategies to improve the quality of inclusive education. By understanding these aspects, a revamping is needed at the societal level in inclusive education for ensuring its quality in practice.

Conclusion: Formation of an inclusive community, the goal is yet to be achieved in India; however, its stepping stones are taken by the educators and professionals in this field. As it's really a hard nut to crack, attitude change within the society is inevitable for it.

Introduction The word autism is derived from a Latin word, auto which means 'self'. The term autism was coined by Leo Kanner in 1943 and the three main features enlisted include abnormalities in communication

abnormalities in social interaction and stereotyped behaviours are still used as diagnostic tools. Autism is a complex bio-neurological disability. Children with autism spectrum disorder (ASD) are challenged by the most essential human behaviours. Autism is characterized by impaired social interaction and communication, and by restricted and repetitive behavior. It is often referred as the triad of 'Triad of Impairment'.

Autism is a neuro-developmental disorder which appears during infancy or childhood, and follows a steady course without remission. Autism appears prior to the age of three and the early symptoms like poor eye contact and lack of social smile begin before the age of six months however, still scientists are unknown to the exact cause of autism. Currently, there is a variety of therapies are available, indeed there is no perfect way to cure autism, and hence parenting a child with autism is really a voyage. Parenting a child with autism spectrum disorder (ASD) has been shown to detrimental effect on marital relations. Featherstone (1980) highlighted, the diagnosis can create powerful emotions in both partners as a symbol of mutual failure. It can restructure the family system entirely and can breed a fertile ground for conflict.

REVIEW

Inclusive education: Global perspective

Globally, Recognition of human rights and social justice is the founding stone in inclusive education. In 1994 the Salamanca document calls for unified education system, it argued for inclusion of all learns in one and thus improve the quality of their education system (UNESCO, 1994). Inclusive education means "attending the age appropriate class of the child's local school, with individually tailored support" (UNICEF 2007).

The major premise of this document called on all government to improve their education system so as to accommodate all with special needs. Second principle was to adopt inclusive educational policy and thirdly, to build liaison with countries practicing inclusive education system. The fourth principle was to develop "decentralized" and "participatory mechanisms" for planning and evaluating the educational provisions available in one's country. The fifth principle is the involvement of families and communities of differently able children for an education system that can include all. Finally, its projects the significance of early identification and intervention acknowledge the need for a systemic change (UNESCO, 1994).

Despite increasing number of children with autism attending mainstream schools, the process of facilitating their learning and participation remains a complex issue and poorly understood area of education (Barnard, Prior & Potter, 2000; Batten, Corbett, Rosenblatt, Withers & Yuille, 2006; Humphrey & Parkinson, 2006).

Furthermore, mainstream school teachers report that they don't have required training and support to provide adequately for the special children. (Robertson, Chamberlain & Kasari, 2003).

Heiman (2004), European countries have accepted inclusion of children with autism in general public school for the last two decades. The four different models of inclusion are 1. In and out 2. Two teachers 3. Full inclusion 4. Rejection of inclusion (as cited in Manisah, Ramlee and Zalizan, 2006). Manisah et al. asserted that teachers in the United Kingdom and Israel prefer the 'in and out' model as it is believed to be more effective for differently able children as they can experience two worlds. Second one is the two teacher model, in which two teachers teaching in the same class simultaneously, with one of the trained teachers aid the special child. The next model is the full inclusion model and Manisah et al. claimed that the teachers involved in this inclusion programme should be given additional support by other teachers in the school setting.

In the study by Manisah, Ramlee and Zalizan, (2006), a few teachers from United Kingdom and Israel rejected the inclusion of students with special needs completely because they thought differently able children should study separately and it's quite difficult to reach the academic level of normal children.

Studies conducted in India (Sharma, Moore & Sonawane, 2009), in Lebanon (Wehbi, 2006), in Nigeria (Fakolade & Adeniyi, 2009) pointed out similar concerns about teacher's lack adequate professional knowledge and skills to work with special children in public schools (as cited in Ballhysa & Flagler, 2011).

Mukhopadhyay & Mani (2002) reported that, 1 percent of children with disabilities between the age group 5-15, had an access to education in India. World Bank Report (2007) reveals that 38 per cent of the disabled children in the age group 6-13 years are out of school. Indeed in India, children with disabilities do not have access to education is a grave issue to be addressed systematically and scientifically.

Mazurik-Charles and Stefanou (2010) reported, when planning interventions for children with autism, different aspects involving impairments in social interaction required priority. Based on this fundamental information, children with autism spectrum disorders who are educated in inclusive classrooms may have call for both social interaction interventions and behavioral interventions so as to effectively learn.

Inclusive education in India

In 1997 the concept of inclusive education was introduced in India by Jangira, on the basis of UK Warnock committee Report. Prior to this, in 1980's the concepts like 'dual teaching model' and multi-skilled teacher plan was prevailed in India. Through practice inclusive education gained momentum in India in 1990's and international advocacy for inclusion contributed largely to it. India adopted world declaration on education for all in 1990. The rehabilitation council of India Act 1992 initiated training programmes for the development of professionals to respond to the needs of the children with disabilities. The government of India passed the National Trust for welfare of person with autism, cerebral palsy, mental retardation and multiple disabilities act, in 1990 for the economic rehabilitation of people with disabilities. Person with disabilities Act (PWD Act) 1995

remains a landmark document which comprehensively covers civil, political, social, economic and cultural rights of person with disabilities.

Furthermore, education is the prime form of management for this unsolved triad of impairment. In inclusive education responsibilities disseminate for schools, teachers and children's parents, as well as the other professionals who work with autism children. The individuals with Disabilities Education Act of 1975 opened a prospect for educating children who face special challenges like autism. Primarily, with the great work by Action for Autism (AFA), the ministry of health in the mid-1990, the government of India now accepted autism as disability.

Indeed, both full-fledged inclusive education programs and quasi-inclusive program are being practiced in various forms by different organizations in India. An ideal inclusive education concept aims at facilitating total integration of the child in the community. The upcoming inclusive education programs in India are avoiding separation of children with disabilities from their families for the purpose of education.

Rationale of the study

Inclusive education for special children opened a new era in the current educational scenario. While analyzing the disability education sector in India, inclusion is still in infancy stage. Indeed, limited research depicts the pros and cons of inclusive education. So the researcher tried to analyses the severity of the issue in depth to trace out the facts related to it. Hence the study implies the stumbling blocks in the journey of inclusive education for children with autism through the eyes of a parent.

Research Design

The research endeavor is a qualitative study with seven parents having children with autism selected from three special schools in Ernakulam district, Kerala. The special schools included in the study are Sneha Sadhan special school, Piravam, Swathanam Special school, Kothamangalam, and Chavara Special School, Koonanmavu. Since it's a qualitative study with case study design, in sampling procedure, purposive sampling is adopted for the study. The primary source of data were the respondents itself that is parents (age 20 to 40) of children with autism below 18 and above 10. Among the seven parents of children with autism, five are fathers and two are mothers and the inclusion criteria set for parents of children with autism is that they should send their children at least one academic year in mainstream school. The Primary data collected through semi-structured interview with parents, while the secondary data from books and journals. Primary data was coded in thematic analysis and four themes were emerged from eight categories through data analysis.

Research Findings

In data analysis, eight categories were evolved and the data coded into four major themes. Four relevant themes emerged through this research includes attitude and knowledge of teachers; school climate and social isolation are discussed below.

Table 1 Thematic Analysis of research findings

Research Question	Themes	Categories
In parental perspective, what are the inclusive educational barriers in autism and how can alleviate it?	Attitude of the teacher Knowledge of the teacher School climate Social isolation	Positive attitude, Negative attitude Inadequate knowledge about Autism Lack of Skillfulness Environmental problem, Inadequate Resources Rejection from peer group, Social Stigma

Barriers perceived by the Parents of Autistic Children in Inclusive Education

1. Attitude of the teacher The first major theme Knowledge of the teacher constitutes two categories like Positive and Negative Attitude. Teacher's attitude plays a vital role in imparting education to the special children. In this study attitude refers to, the degree of their willingness to teach an autistic child in the inclusive education. If the teachers are inclined to receive the autistic child, it depicts their positive attitude towards the special children. It is illustrated through the wordings of the third respondent, mother of an autistic boy.

Don't worry about your child. He is okay. I can manage him in the class. Don't worry dear.

The teacher applied some techniques to manage his behavior problems and thus the teacher can handle him easy. On the flips side, it's really a tedious task for the teachers to accept an autistic child in their classroom, as the seventh respondent of the study, mother of an autistic boy recollected the wordings of a teacher.

Since autism affects the mind of a child, it's too difficult to handle the behavior issues of the child compared to the children with other type of disabilities.

It reflects the negative attitude of the teacher towards the children with autism. It calls for an attitude change within the academic fraternity by focusing on the strength of the child. All these imply the two extreme dimensions of attitude, both positive and negative attitude of teacher, which determines the quality of inclusive education to a great extent.

2. Knowledge of the Teacher

The second major theme Knowledge of the teacher constitutes two categories like inadequate knowledge about Autism and lack of Skillfulness.

Inadequate knowledge about Autism: Knowledge of the teacher means the expertise possessed by the teachers in teaching both the children with autism spectrum disorder (ASD) and normal children in inclusive education. Furthermore, teachers who are equipped with knowledge and skills can only cater the needs of both children with and without autism. Teachers should have basic understanding about autism, causes, symptoms and co-morbidity conditions. Unfortunately, it's a fact that teachers in the mainstream schools don't have adequate knowledge about autism. It can be illustrated through the wordings of the fifth respondent of the study, mother of an autistic girl.

Teachers never take an initiative to identify the skills in the autistic child. They think in terms of academics only.

Lack of Skillfulness: It reveals the fact that sufficient knowledge about the management of autism is inevitable for an efficient teacher. Skillfulness refers to the ability of the teacher to apply his knowledge for the overall development of the child. School authorities are not concerned about imparting adequate training for enhancing the teachers' skill in inclusive education system. For example, fourth respondent father of an autistic boy recollected the wordings of a teacher.

I am unable to manage the behavioral issues of the child as I didn't get required training in this matter. I am totally discontented.

It reflects the need for imparting adequate training and knowledge to the teachers to increase the quality of teaching. One of the qualities of a good teacher is the willingness to learn essential skills needed for accepting and teaching special children in inclusive programme.

3. School Climate

The third theme was characterized by two categories like Environmental problem and Inadequate Resources. Environment plays a crucial role in teaching the children with autism.

Environmental problem: Environmental problem refers to the hurdles that a teacher has to encounter when teaching an autistic child in the mainstream school. It includes class condition, time restriction, student's strength and communication problem. It's quite evident from the wordings of sixth respondent of the study, father of an autistic boy.

Teacher has to repeat the instruction personally to the child to speed up his action. Teacher has to spend more time and attention to the autistic child, neglecting the normal children in the class.

There is difference in the learning capacity and learning speed of normal children with the autistic child. To overcome that, teacher has to spend more time with the autistic student as the students are in need of more explanation about the lesson. Due to the poor cognitive ability children with Autism Spectrum Disorder have a short term focus in the class. It means that the children with autism are unable to concentrate from beginning to the end of the class. Thus the teacher needs to provide much attention and guidance to the children with autism. Indeed, in order to resolve the environmental hurdles like class condition, time restriction, student strength and communication problems, effective strategies need to be devised in line with the school climate.

Inadequate Resources: Inclusive education demands sufficient infrastructure facilities for teaching the children with autism spectrum disorders in main stream schools. Play devises are used to retain attention and memory of special children. In addition to this, assistance from the special educator or shadow teacher should be available to the normal school teachers. But in reality, it is quite difficult to practice as explained by a mother of an autistic girl child, first respondent of the study.

Shadow teacher will accompany the autistic child in the class. Teacher will teach all the students in the class, and the shadow teacher will help her to learn. However, it is inadequate to train the autistic child to improve social skills and learning capacity.

From her statement it is clear that teaching an autistic child in the absence of resource teacher is really a hectic task for the mainstream school teachers and sufficient teaching aids should be provide to the teachers to tackle the issue effectively.

4. Social Isolation: Social isolation as a major theme consists of two categories such as rejection from peer group and social stigma. Children with autism prefer to live in their own world, on the flip side due to their innocent nature the autistic child would be target for bullying by other students.

Rejection from peer group: Autistic child had severely impaired communication skill and social interaction. Due to their poor understanding of social situation and inability to differentiate between rights and wrong the autistic child become the victim of verbal, physical and psychological abuse. According to the seventh respondent of this study, mother of an autistic boy,

Friends asked him to go and look at the girls' toilet. Without knowing its difference he went to the girls' toilet and girls terribly feared and screamed. At last teachers came, scolded and punished him.

Bullying, teasing and these kinds of psychological alienation by peers imply the rejection experienced by the autistic children in mainstream school. Hence, it's a critical issue which needs much attention and supervision from teachers and school authorities.

Social stigma: Behaviour problems associated with autism includes self injurious nature, aggressive nature, mood swings and hand flapping etc evolves a kind of fear and aversion in mainstream children towards the autism children. It can be illustrated through the statement by the second respondent of the study; mother of an autistic boy is given below.

The autistic child may daydream, and sometimes he is singing or sometimes crying. Besides he makes loud voice and sometimes walks continuously without considering the social context.

Broadly speaking, the behavior problem can be categorized into two types namely over involvement and isolating oneself, which demands teachers special attention and time. On the other hand, these behavior issues generate awardees and social stigma in normal children for the autistic children.

The autistic children's innocent nature is exploited by the peer group friends. Both rejection from peer group and social isolation results in psychological issues like low self esteem and depression in children with autism.

To summarize, this qualitative research examined the parent's perception on inclusive education through a variety of experiences they had with mainstreaming their children through the inclusive educational system. Four relevant themes emerged through this study includes, attitude and knowledge of teachers, school climate and social isolation. Findings highlighted the significance of developing certain strategies to improve the quality of inclusive education. By understanding these aspects, a revamping is needed at the societal level in inclusive education for ensuring its quality in practice.

Suggestion

The results of study imply the significance of working on the scholastic context at different levels such as physical environment and classmates to cater the needs of the special children.

In addition to this, sharing knowledge both by professional and by parents can contribute simultaneously to the overall development of the child as each child is unique in their needs and skills.

From a social policy perspective, policy makers and professionals in this field can be recommended for a positive school ethos and commitment to inclusion, characterized by a top-down commitment and clear channels of communication from head to teachers.

Future research should explore the various ways of coping for both teachers and students in inclusive education system that will shed light into the quality of inclusion.

A final point to consider here is that, inclusion as a never ending process, grounded in the collaboration and cooperation of various social agents like school administrative staff, teachers, non teaching staff, classmates, the entire family system and society.

Conclusion

Put it in a nutshell, this study will provide an insight into how children with autism can be included in the mainstream classroom successfully and can therefore provide a framework for parents and teachers who are facing the issue of school placement for their children with autism.

Formation of an inclusive community, the goal is yet to be achieved in India; In fact, the gap between the 'inclusion rhetoric' and 'classroom reality' was very wide. However, its stepping stones are taken by the educators and professionals in this field. As it's really a hard nut to crack, attitude change within the society is inevitable for it.

REFERENCES

Books

Kumari, M. (2009). Overview of different disabilities. In *Education for the children with special needs* (First ed., Vol. 1, pp. 30-45). Daryagan, Delhi: Centrum press.

Barnard, J., Prior, A. & Potter, D. (2000). *Autism and Inclusion: Is It Working?* London: National Autistic Society.

Batten, A., Corbett, C., Rosenblatt, M., Withers, L. & Yuille, R. (2006). *Make School Make Sense: Autism and Education*. London: The National Autistic Society.

Journals

Ballhysa, N. & Flagler, M. (2011). A teachers' perspective of inclusive education for students with special needs in a model demonstration project. *Academicus – International Scientific Journal*.

Girli, A. (2012). An examination of the relationships between the social skill levels, self concepts and aggressive behavior of students with special needs in the process of inclusion education. *Cukurova University Faculty of Education Journal*, 42(1), 23-38.

- Manisah, M.A., Ramlee, M. & Zalizan, M.J. (2006). An empirical study on teachers' perceptions towards inclusive education in Malaysia. *International Journal of Special Education*, 21(3), 36-44.
- Rovira, A. A. (2014). Enhancing social behavior of children with autism in an inclusive classroom. *Senior Theses and Capstone Projects. Paper 6*. Retrieved from <http://scholar.dominican.edu/cgi/viewcontent.cgi?article=1003&context=senior-theses>
- Mazzer, M. (2015) Inclusion of Students with Autism Spectrum Disorders in Italian Schools: From Theory to Practice. *Open Journal of Social Sciences*, 3, 91-96. <http://dx.doi.org/10.4236/jss.2015.39014>
- Humphrey, N. & Parkinson, G. M. (2006). 'Research on interventions for children and young people on the autistic spectrum: a critical perspective.' *Journal of Research in Special Educational Needs*, 6, pp. 76–86.
- Robertson, K., Chamberlain, B. & Kasari, C. (2003) 'General education teachers' relationships with included students with autism.' *Journal of Autism and Developmental Disorders*, 33, pp. 123–30.
- Mazurik-Charles, R. & Stefanou, C. (2010). Using paraprofessionals to teach social skills to children with autism spectrum disorders in the general education classroom *Journal of Instructional Psychology*, 37(2), 161-169.
- Kumari, M. (2009). Overview of different disabilities. In *Education for the children with special needs* (First ed., Vol. 1, pp. 30-45). Daryagang, Delhi: Centrum press.
- Barnard, J., Prior, A. & Potter, D. (2000). *Autism and Inclusion: Is It Working?* London: National Autistic Society.
- Batten, A., Corbett, C., Rosenblatt, M., Withers, L. & Yuille, R. (2006). *Make School Make Sense: Autism and Education*. London: The National Autistic Society.