

## **Parents' Attitude toward Inclusion of their Children with Autism in Mainstream Classrooms**

Shivani Mathur, University of Rajasthan, India  
Kavita Koradia, University of Rajasthan, India

### **Abstract**

Despite the growth of inclusive education programs adopted by many schools across India, children with special needs rarely find themselves included in them. Autism being a pervasive disorder, it becomes hard for autistic children to communicate and express themselves in a socially appropriate manner. Hence, the objective of this study was to explore the perceptions of parents about inclusion of children with autism in mainstream classrooms. A sample of 20 parents whose children were already enrolled in a mainstream school was selected from a school in Jaipur, Rajasthan, India. Participants were assessed on Parent's Attitudes to Inclusion (PATI, 1998). The result of the study showed the attitude of parents towards the quality of educational services in mainstream education is negative; whereas, when it comes to child acceptance and treatment in mainstream education the parents have a positive attitude. It was also found that parents of children with autism have a neutral attitude towards the mutual benefits of inclusive education. The findings also revealed that regardless of their positive outlook, parents had certain conjectures about such inclusivity. These pertained primarily to childcare responsibilities, children's transition tasks and teachers' challenges of managing everything effectively while teaching both students with and without diagnosis of autism in the same classroom. This study can be used by special educators, school authorities and teachers teaching in an inclusive classroom to better understand the concerns of parents of children with Autism Spectrum Disorder (ADS).

**Keywords:** autism, inclusive education, mainstream education, special education

## Introduction

Autism Spectrum Disorder (ASD) is a neurological disorder typically diagnosed in childhood and has a wide range of symptoms, varying in their severity. These symptoms mainly consist of three basic factors that are communication, socialization/behavioral and interest impairments, as well as minimal social skills (Weiss, Wingsong & Lunsky, 2013). Due to these indicators, a child with ASD diagnosis faces challenges relating to peers and forming meaningful relationships. As well, there has been an increase in such diagnosis over a short period of time. Approximately 18 years ago, cases of autism ranged from five per 10,000 (American Psychiatric Association, 2000) to 60 per 10,000 (Altiere & von Kluge, 2009); today, this is as common as one in 59 children (Baio, Wiggins, Christensen, et al., 2018). At present, ASD has become widely prevalent, with males being affected 4.5 times more by this diagnosis than females (Rice, 2009).

Children diagnosed with autism may communicate verbally, nonverbally or a combination of both, depending on the severity and treatments/therapies they receive. Due to this aspect of autism, it is difficult to include them within mainstream education systems. Children with diagnosis of autism require special attention and thus, school curriculum and special education services may need to be modified in accordance to their individuality. Also, inclusive education brings with it problems that are related to the other children in the classroom and their parents. Although inclusive education is now a part of Indian legislation, it is extremely difficult to change the mindset of people regarding children with special needs. In an inclusive classroom, child diagnosed with autism are often looked upon by their peers as being socially awkward.

To define inclusive education, it may be enumerated as an approach that addresses the learning needs of all children. Inclusive education is a medium that allows children with special needs to withstand and receive education, training, schooling or learning in any form in mainstream classes. Although inclusive education is a relatively new concept in India, supporters of such education believe children with special educational needs can achieve wonders in mainstream education programs, provided they are given additional aids and services. Inclusive education requires all learners – children with differing abilities – study and grow together through access to common pre-school provisions, schools and community educational settings with an appropriate network of support services. This is possible only in a flexible education system that is ready to assimilate the needs of a varied range of learners and adjusts itself to meet the needs of all children. Such a system not only helps the children but all stakeholders involved – the learners, parents, community, teachers, administrators and policy makers – to cope with diversity in a positive way and see it as a healthy and positive challenge rather than a major problem.

Both extant research and anecdotal reports by practitioners have shown that parents' perceptions are of great importance in determining the success of such inclusion, as parents are the second teachers and most responsible for implementing inclusive service delivery models.

## Challenges Faced by Parents of Children with ASD Compared to Parents of Typically Developing Children

Parents of children diagnosed with Autism Spectrum Disorder (ASD) face numerous challenges that cause them to experience substantial complications compared to other parent groups. Overall, the psychological impact of caring for a child with ASD is reported to be massive for parents (Cullen & Barlow, 2002). Studies show these parents reported more stress

compared to parents of Typically Developing (TD) children and were found to be approximately three times as vulnerable to psychological and physical complications (Brobst, Clopton, & Hendrick, 2009; Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Gau et al., 2012). The first study to determine that parents ( $n=67$ ) and siblings ( $n=37$ ) of children with ASD obtained significantly higher scores of in depression scales compared to parents and siblings of TD children was conducted by Piven and colleagues (1990). Any indiscretions or disruptions in daily routines elicited anxiety in children with diagnosis of ASD and their mothers; also, the children's difficulties in participating in activities, their struggles to communicate, and disturbing behaviors, triggered anxiety in their mothers (Larson, 2006). The children's disruptive behaviors or autism-related symptoms seemed to be significant determinants in parents' mental health status, with the latter experiencing lower levels of distress as their child's behavior improved over time and became less disruptive (Gray, 2006; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009).

As well, King, Greenberg, and Seltzer (2010) conducted a study with 406 mothers of children of various ages with diagnosis of ASD to find that children's health problems were a direct source of stress for mothers, as such concerns in children usually led to behavioral problems that increased the mothers' stress levels. Approximately 41% of parents of a child with diagnosis of ASD described experiencing some form of emotional, physical, financial, or marital relationship stress difficulties compared to parents of TD children (Higgins, Bailey & Pearce, 2005; Lecavalier, Leone, & Wiltz, 2006). A study conducted by Ingersoll and Hambrick (2011) revealed that 56% of parents of eight-year-old children with diagnosis of ASD obtained significant scores in depression scales, and 85% of parents scored in the clinically significant range for parenting stress. It appeared that mothers and fathers of a child with diagnosis of ASD were pretentious and contrary in their mental health status, with mothers being more negatively affected by their child's impairment than fathers (Ekas, Lickenbrock, & Whitman, 2010). Similar results were observed in a study conducted by Davis and Carter (2008), in which more mothers (33%) of toddlers diagnosed with ASD than fathers (17%) reported clinically significant depressive symptoms. Further, mothers who did not have a husband or a partner were more likely to be depressed than married mothers (Ekas et al., 2010).

In a study by Benjak, Vuletic Mavrinac, and Pavic Simetin (2009) it was discovered that parents of children diagnosis of ASD reported significantly poorer self-perceived health compared to parents of TD children. Energy, vitality and social functioning were particularly low dimensions of self-perceived health. The only dimension of health in which there was no difference with the parents of TD children was physical health, which can be explained by the fact that 71% of surveyed parents with children with diagnosis of ASD were under 50 years of age. Another interesting finding was that 35% of parents of autistic children perceived their health as worse compared to the previous year, and this was 18% higher in comparison to parents of TD children. This discrepancy in self-perceived health between parents was confirmed by the finding that 41% of parents of children diagnosed with autism as opposed to 30% of parents of TD children who reported the existence of a chronic medical condition.

The stress experienced by parents of children with diagnosis of ASD was a strong predictor of heightened risk of divorce (Hartley et al., 2010). However, even though such parents reported more emotional stress, they remained more resilient compared to parents of TD children (Lam, Wong, Leung, Ho, & Au-Yeung., 2010). According to a study conducted by Lai, Goh, Oei, and Sung (2015) parents of children with diagnosis of ASD reported significantly more parenting stress symptoms such as negative parental self-views lower satisfaction with the parent-child bond, and more depression symptoms, than parents of TD children. Despite

findings such as these which suggest that parents of children with diagnosis of ASD are more anxious and depressed and under greater pressure than parents of TD children, the field has rarely focused on an in-depth investigation of psychological outcomes for this parent group (Benderix, Nordström, & Sivberg, 2006). Researchers such as Krauss, Seltzer, and Jacobson (2005) have argued that in-depth investigations into mental health outcomes have been difficult to initiate with parents of children with diagnosis of ASD because they are overburdened with numerous and long-term responsibilities in caring for their child during childhood, adolescence and adulthood as autism is a lifelong condition.

Parents of children with autism also appear to be in greater distress when compared to parents of children with differing abilities. For instance, the level of general stress experienced by parents of a child with autism was significantly higher than for parents of a child with Down Syndrome (DS) (Dabrowska & Pisula, 2010). Studies conducted with mothers of children with diagnosis of ASD have reported higher levels of parenting stress and psychological distress than mothers of a child with Developmental Delay (DD) (Estes et al., 2009). Studies comparing parents of children with autism with parents of children with other developmental disorders in relation to mental health status and coping strategies (Estes, et al., 2009; Greenberg et al., 2004) have generally reported that the former report more parenting stress and psychological distress compared to parents of children with other differing abilities.

### **Value of Inclusion**

Educational inclusion entails rights of children to enroll themselves with non-disabled peers and add an opportunity to learn along with non-disabled children. The inclusion movement, like its prototypes in mainstreaming and integration movements, has been “driven by values regarding increasing acceptance of diversity in classrooms” (Coots, Bishop, & Grenot-Scheyer, 1998, p. 317; see, also, Dorries & Haller, 2001; Pereira Dos Santos, 2001). The concept of inclusive education has been extended to address socially constructed and contextual aspects of diversity, arising from ethnic opportunity and linguistic barriers to effective education (Elkins, van Krayenoord, & Jobling, 2003), but access to regular education for children with special needs which is the focus of the present study that is aimed at a person-based diversity.

In practice, the right of children with special needs to be enrolled in regular schools and to be included in regular classes has created difficulties. Parental aspiration, teacher expertise, school resources, and system policy have influenced how this right is exercised. Parents and educators often hold conflicting views, with the issues confronting parents and schools typically seen as multidimensional (e.g., appropriateness of educational services, reciprocal benefits, the social context for learning). Attitudinal research on inclusion has confirmed multiple, sometimes discrepant, and ultimately unresolved perspectives on people's attitudes (Elkins et al., 2004). Therefore, the process of finding consensus and identifying areas of agreement traverses a range of educational issues based on what is affirmed and what is experienced.

Perhaps it is because achieving consensus about inclusive acceptance among stakeholders is such a dynamic process, that studies of general attitudes towards inclusion and its benefits (i.e., what stakeholders want and why they want it) have continued to attract maximum research effort. The need to articulate who to include, why to include and when to include has maintained a research focus on perspectives, values, and beliefs (Bond & Hebron, 2016). The present study acknowledges this diversity of views, in opting to target the specific points at which parent responses affirm or depart from a general consensus with other parents of children with autism.

## Rationale

In the recent past, studies have been conducted on children with special needs, but so far it has been focusing on education/rehabilitation programs for children and teachers' experiences at large. The fact is that parents also undergo continuous and tremendous stress and face difficulties while their child is in a mainstream school. It is worthy to understand the perspective of parents regarding inclusive education. Thus, this study was designed with the following objectives.

## Objectives

1. To conduct the item-wise analysis of parents' attitude towards the mainstream education of their children obtained from PATI scale.
2. To explore parents' attitude towards the quality of educational services in mainstream education.
3. To explore parents' attitudes towards child acceptance and treatment in mainstream education.
4. To explore parents' attitude towards the mutual benefit of mainstream education.

## Participants

As illustrated in Figure 1, total number of participants was 20 parents, equally divided between fathers and mothers of already diagnosed children with ADS who were in mainstream schools. The sample was collected within the premises of Jaipur city. The purposive sampling technique was used to obtain data.

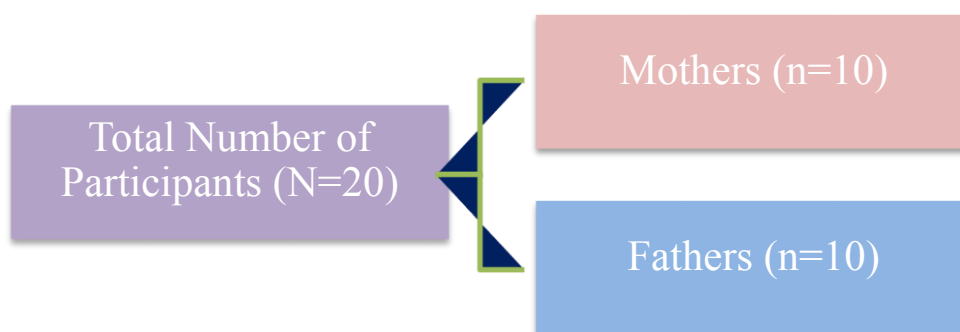


Figure 1: Sample Distribution

## Measures

1. **Base Line Proforma:** This contains background information about the participants such as age, education, qualification, income, and so on. Basic information about the child was also taken such as age of diagnosis, severity, mental and chronological age, birth order, and so forth, along with few important questions about day-to-day routine of the child.
2. **Parent's Attitude to Inclusion (PATI):** This was developed by Palmer, Borthwick-Duffy, and Widaman (1998) to understand the attitude of parents towards inclusion of their children in mainstream classrooms. The tool consists of 10 questions that deliberately incorporate the "multidimensional nature of parent perceptions regarding inclusive practices for children with significant cognitive disabilities" marked on a 5-point Likert scale.

## Results and Discussion

The data collected for this study was analyzed using descriptive statistical methods. The findings explained below in Table 1 are based on the objective set for the study.

Objective 1: To conduct item-wise analysis of parents' attitude towards the mainstream education of their children obtained from PATI scale.

Score	Item 1		Item 2		Item 3		Item 4		Item 5		Item 6		Item 7		Item 8		Item 9		Item 10	
	F	%	F	%	F	%	F	%	F	%	F	%	F	%	F	%	F	%	F	%
Strongly Agree (5)	0	0	14	70	0	0	6	30	0	0	7	35	0	0	0	0	6	30	8	40
Agree (4)	1	5	6	30	13	65	3	15	11	55	12	60	3	15	3	15	6	30	8	40
Neutral (3)	4	20	0	0	4	20	0	0	4	20	1	5	4	20	0	0	3	15	1	5
Disagree (2)	12	60	0	0	3	15	9	45	2	10	0	0	13	65	13	65	5	25	3	15
Strongly Disagree (1)	3	15	0	0	0	0	2	10	3	15	0	0	0	0	4	20	0	0	0	0
TOTAL	20	100	20	100	20	100	20	100	20	100	20	100	20	100	20	100	20	100	20	100

Table 1: Item-wise Analysis of Parents' Attitude towards Mainstream Education

Table 1 shows the scores and its percentage of 20 parent's response to each item on the PATI scale. The first item in the PATI scale is *the more time my child spends in a regular classroom, the more likely it is that the quality of his/her education will improve* and 60% of parents showed their "disagreement" to this statement. It shows majority of parents do not have faith that if their child diagnosed with autism spends more time in the mainstream classroom, it increases the quality of their education.

The second and third items in the scale aim to explore parents' attitude towards child acceptance and treatment in mainstream education. Item 2 stated *the more time my child spends in a regular classroom, the more likely it is that he/she will be mistreated by other nondisabled students in that room* and 70% parents strongly disagreed with this statement and showed their positive attitude. The third item in the scale was *the more time my child spends in a regular classroom, the more likely it is that he/she would end up feeling lonely or left out around the regular education students*. For this statement, 65% parents agreed, while 15% parents showed neutral attitude. From the response, it can be concluded that most of the parents of children

with autism agree inclusive or mainstream education is nurturing the value of acceptance and positive treatment towards children with special needs.

Item 4 stated *it is impossible to modify most lessons and materials in a regular classroom to truly meet the needs of my child* and 45% of the sample disagreed with this statement and expressed their negative attitude towards this. Item 5 in the scale was *if my child were to spend a lot of time in a regular classroom, he/she would end up not getting the extra help he/she needs* and 11 participants out of 20 (55%) agreed and showed positive attitude towards the comprehensive approach in mainstream education for the children with autism.

For the 6<sup>th</sup> statement in PATI, *if my child were to spend much of his/her day in a regular classroom, he/she would become friends with nondisabled students in that room* and 95% participants showed their positive attitude towards this and agreed their children will get more non-disabled friends if they spend much time in regular school.

Item 7 in PATI is about the mutual benefit of inclusive education. This stated *the quality of a regular education student's education is enriched when a student with severe disabilities participates in his/her class*. To this, 13 (65%) participants disagreed, while 4 (20%) participants took a neutral stand. It can be inferred that parents of children with autistic do not believe quality of general education will be improved when their children are present in the mainstream classroom.

The eighth and ninth items in PATI compare services provided in mainstream and special schools. The majority of respondents (85%) showed their negative attitude in discontinuing the services of special schools for children with autism. The response to Item 9 in PATI indicate 60% of parents agreed their children are getting more services and opportunities in mainstream schools than regular schools.

The tenth item in PATI scale was, *the more time my child spends in a regular classroom, the more likely it is that he/she will be treated kindly by the nondisabled students in that room*. To this, 80% participants agreed typically developing children will understand and their child will be treated more kindly if their child spends more time in the regular classroom.

Objective 2: To explore the parents' attitude towards quality of educational services in mainstream education

N	MEAN	S.D
20	2.38	1.3

Table 2: Mean and SD of Parents' Attitude towards Quality of Educational Services in Mainstream Education

To assess parents' attitudes towards quality of educational services in mainstream education, items 4, 5, 8 and 9 on PATI scale were computed. Table 2 shows the result of the analysis. The mean value 2.38 depicts attitude of parents towards quality of educational services in mainstream education is negative. It could thereby be concluded that parents are not satisfied with existing measures to improve quality of mainstream education.

This result suggests that provisions such as preparation and competence of teachers, both at initial and at the in-service level, and the provision and possible training of non-teaching support staff is needed to provide quality education. Greater linkages between mainstream and special schools with pupils going back and forth or special school staff acting as outreach support teachers in mainstream settings and vice versa, is a further possibility to enhance quality. The increased promotion of an inclusion agenda as a feature of other educational and governmental initiatives should be considered.

Objective 3: To explore the parents' attitudes towards child acceptance and treatment in mainstream education

N	MEAN	S.D.
20	4.03	0.85

Table 3: Mean and SD of Parent's Attitudes towards the Child Acceptance and Treatment in Mainstream Education

Items 2 and 3 in PATI were studied to find out parents' attitudes towards child acceptance and treatment in mainstream education. The mean value is 4.03, which shows parents have a positive attitude towards child acceptance and treatment in mainstream education.

Parents often have two concerns: interactions with peers and quality of education programs. However, parents of children in inclusive settings reported very few difficulties with peers and agreed that inclusive settings promote positive social contact for all children. Many parents of children with disabilities want their children to form friendships with typically developing children and reap the benefits of real-world experiences offered by the school.

Objective 4: To explore the parents' attitude towards mutual benefit of mainstream education

N	MEAN	S.D.
20	3.30	1.23

Table 4: To explore the parents' attitude towards mutual benefit of mainstream education

In order to find the attitude of parents with autistic children towards the mutual benefit of mainstream education, this study used items 1, 6, 7, and 10 on the PATI scale. The mean value is 3.30. It can be inferred attitude level of parents is neutral. The result of the study throws light on the need of awareness among parents regarding the benefit of inclusive education for all children in the classroom.

## Conclusion

Based on the results of this study, in general it may be averred that inclusive programs have received both positive as well as negative responses from parents. Studies have shown the success of inclusive education depends, to a large extent, on the readiness and aptitude of all



stakeholders, most importantly parents, to make room for individuals with special needs. In conclusion, interviews with parents serve to confirm the common arrangement on a general right to inclusion and the need for extra support and training to all. Regardless of agreement about inclusion, attitude of parents remained mixed about practices related to inclusion.

The findings that emerged from the current study are supported by results of prior studies which argued that students, teachers and other main stakeholders in an inclusive classroom are more inclined to successfully include students with ASD, if they are knowledgeable about applying effective guidance strategies to meet the needs of such students (Lindsay, Proulx, Thomson, & Scott, 2013; Smith et al., 2000). Furthermore, past studies noted teachers who have knowledge and experience in this regard are more motivated to display a positive attitude and offer support regarding including students with ASD (e.g., Wilkerson, 2012; Simpson et al., 2003).

Additionally, findings from the present study and those from previous research suggest that the attitudes of teachers, students, and parents of TD children regarding inclusion are heavily dependent on the severity of the disorder (Lindsay et al., 2013; Segall et al., 2012; Smith & Smith, 2000; Wilkerson, 2012). Moreover, it highlights the importance of collaboration among parents and school administrations in order to effectively meet the needs of students and facilitate greater success (Hart et al., 2011; Leach & Duffy, 2009). The present study and many others emphasize the importance of ensuring that strategies and practices are kept in unison between the home and school environment (e.g., Hart et al., 2011; Leach & Duffy, 2009).

The findings of the present study validated insights gained from previous literature by rediscovering the fact that some teachers lack resources that can be implemented in classrooms to help autistic students achieve greater success (Lindsay et al., 2013; Smith & Smith, 2000). However, the present study also offered new insights regarding physical adaptations that can be established in the classroom to help students diagnosed with ASD experience greater success. Additionally, the findings revealed more strategies should be developed to help increase behavioral skills for autistic students.

The present data further revealed parents have a positive attitude regarding academic outcome that are established when students with ASD are educated in inclusive classrooms and reinforced the social benefits when interacting with their TD peers daily.

## **Implications**

This study highlights the effort on the part of schools to find significant and creative ways for parents of children diagnosed with ASD to participate and contribute to the school community so that their attitude becomes positive towards inclusion. The study is also relevant for special educators, counselors and teachers of inclusive educational systems to understand the environment and help parents cope well with difficult situations. Moreover, this study sheds light on certain areas of concerns for parents and can be used as a base for an intervention program to equip parents.

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**Corresponding author:** Shivani Mathur  
**Email:**shivanimathursaharia@gmail.com