

Perspectives and Experiences of Parents of School-Aged Children on the Autism Spectrum about Inclusive Schooling in an Urban Indian Context

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Abstract

International policy emphasises inclusive education for children with special needs and acknowledges parental roles in their education. Literature evidence also supports this. Despite India being a signatory to the Salamanca Statement and having adopted policies for the same, parents have been relegated only to carer roles in the recent Rights of People with Disabilities Act (2016).

It is therefore important to know what the expectations and experiences of parents involved in the education of these children are, within the Indian context.

The current study was undertaken to gain insights into the perspectives and experiences of parents of children with autism about inclusive schooling in Bangalore, India. A purposive, convenience sample was utilised to collect data through semi-structured interviews as well as a questionnaire with a few open-ended questions. Fifteen parents of children with autism participated to provide responses to the questionnaire.

The findings indicate that parents perceived inclusive schooling as a “stepping stone to societal integration” and were largely satisfied with their experiences. Parents stressed on the lack of knowledge and training amongst general education teachers, the significant role of school principals and management as also the need to include parents as collaborators in their children’s education. Yet another key point that emerged was regarding the gap that exists between policy and practice in the inclusive education of children with autism.

Keywords: Inclusive education/schooling, Autism, India, Parental perspectives/experiences, Children with special needs

Introduction

Inclusion demands the acceptance of persons from all sections of society. Exclusion has been associated with poverty, gender, race or disability and raising awareness and exposure to differences are factors contributing to the success of social inclusion. In the context of individuals with special educational needs an emphasis on accepting and respecting individuality provides avenues for the achievement of inclusion. In the context of inclusive education, this should involve schools in providing all students the opportunities to attain curriculum goals and positive social interactions with teachers and peers, thereby helping in their emotional development and leading to decreased rates of exclusion (UNESCO, 2009). The Salamanca Statement and Framework for Action on Special Needs Education (UNESCO 1994) describes an inclusive school as one where students with varied needs can learn together and obtain quality education thus providing better opportunities for social inclusion of children with special needs (CWSN).

However, as the research reported in this paper was conducted in an Indian context, it is important to look into the legislation and policies passed by the Government of India (GOI). These are several and include the Persons with Disabilities (PWD) Act, 1995, SarvaShikshaAbhiyan (SSA), the Right of Children for Free and Compulsory Education (RTE) Act of 2009 and the Rights of Persons with

Disabilities (RPWD) Act, 2016. Among these, the PWD Act, (Government of India 1995) was the first legislation that proposed the integration of CWSN into regular mainstream schools (MSJE, 1996). However, it was the RTE Act, (MHRD, 2009) that directed, that parents should be part of school management committees. Chapter V of the PWD Act, 1995 emphasises the right to free education up to 18 years for CWSN. The SSA Framework for Implementation of education for all, outlines roles for parents in the inclusive education of their CWSN and emphasises the need for more research into the practical experiences on inclusive education.

Rationale for the research

Autism (ASD) is a spectrum disorder with wide variations in symptomatology. The *Diagnostic Statistical Manual of Mental Disorders- Fifth Edition (DSM-V)* (American Psychiatric Association, 2013) describes ASD as a complex neurodevelopmental disorder characterised by deficiencies in social interaction and communication along with stereotypical behaviours. The skills deficits identified have often led to exclusion from an inclusive schooling experience resulting in marginalisation of individuals with autism and their families from a wider societal participation. The Salamanca Statement states that for inclusive schooling to succeed, all stakeholders in the process; parents, teachers and school managements must work together. Among these stakeholders, parents are considered to be critical partners and should be included as participants and decision makers in all decisions affecting their child. It is imperative that parental opinions regarding inclusive education and their experiences on inclusive schooling should be researched and understood.

The Research Context

The research was conducted in Bangalore, where the researcher is active in the community of parents of children with ASD. Bangalore has many private mainstream schools that are implementing inclusive practices, though these vary in interpretation and application. The local community of parents of children with ASD is strong both in numbers and the initiatives which they have instituted. The numbers of children with autism attending inclusive mainstream schools is significant. This assisted the researcher in obtaining a sample of parent participants who had the information necessary to inform the research and to address three questions:

1. What are the perspectives of parents of school-aged children with autism about inclusive schooling?
2. What are the actual experiences of the parents of school-aged children with autism with regard to inclusive schooling?
3. How are the perspectives, expectations and actual experiences of parents interlinked?

The sample comprised parents of children with autism identified in two categories. 1)parents who had children in the age group 6-14 studying in private inclusive schools in Bangalore (inclusive setting case participants). 2) parents whose children (age group 6-14) had studied in inclusive schools in Bangalore but were compelled to opt out for varied reasons (non-inclusive setting case participants). All parents included in the research study were university educated. Most of the parents and children were conversant in English and used it as first preference, however, were more confident in other regional Indian languages. The parents were recruited from the autism parent support group in Bangalore.

Research Methods

A purposive convenience sampling procedure was used to recruit parent participants. A mixed methods approach which combined interviews, and questionnaires provided a framework for data collection. Semi-structured interviews allowed the flexibility to pursue non-verbal cues and specific lines of response that emerged during the interview which was important considering the topic being studied. An interview schedule was designed and piloted prior to conducting substantive interviews. Four interviews were conducted, the participants being chosen specifically to gather information about aspects of inclusive schooling of children with autism. Data from these interviews informed development of the questionnaire. All the interviewees were informed of the purpose of the research

prior to meeting and the interviews were conducted in English, ranged in length from 30 minutes to one hour.

The questionnaire sample were identified from the same parent support group. Fifteen parents of children with ASD aged between 6-14 years, who were currently attending inclusive schools were selected for this purpose. Each of the participants was contacted by phone and on receiving oral consent, an information sheet and the consent form was provided.

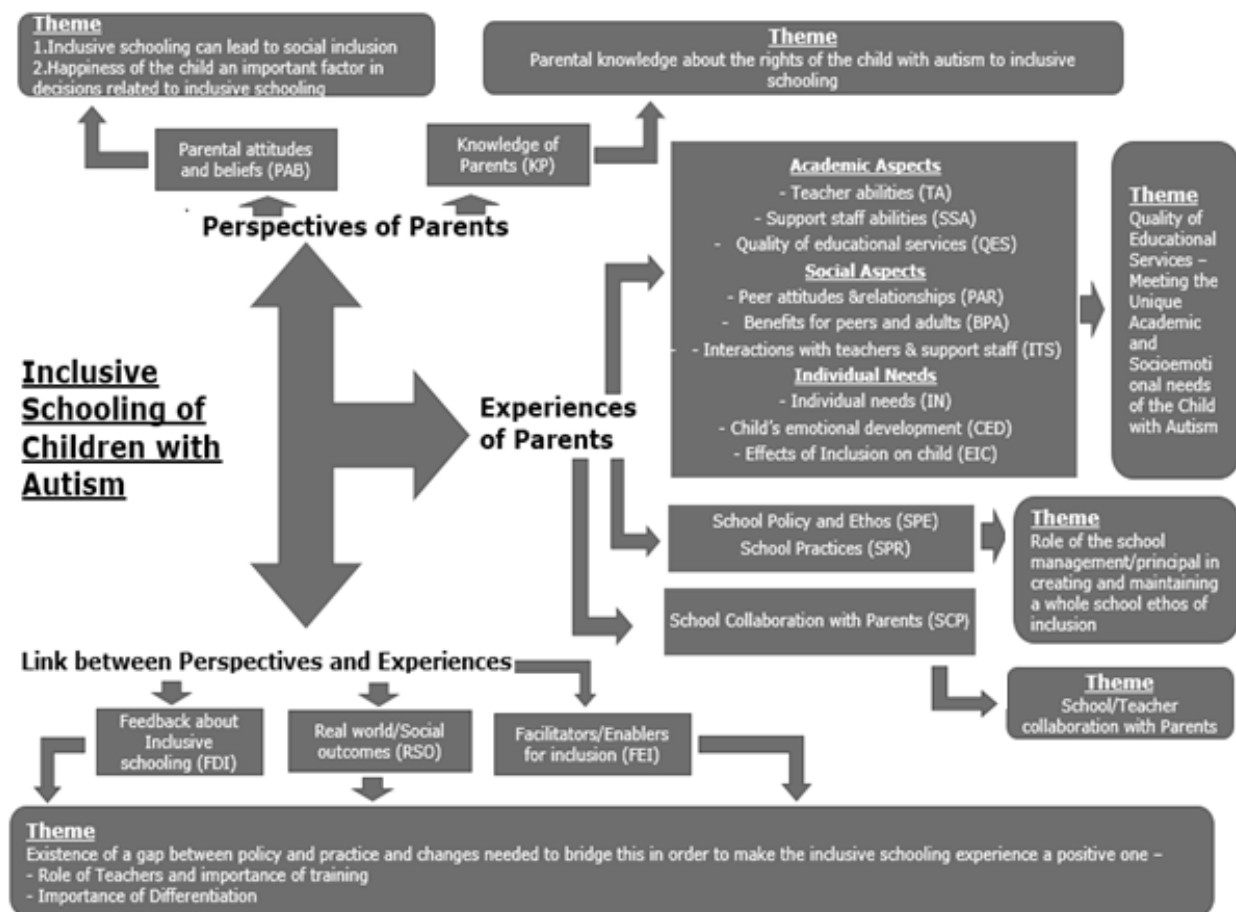
The questionnaire comprised two sections; a background information sheet and a set of questions related to the focus of the investigation. The background information sheet obtained demographics about the parents and their children. This comprised of a set of 12 questions with the first seven related to the parent and the remaining five about their child with autism. Participants were asked to state the kind of school the child was currently attending and whether the child's diagnosis was known to the school.

The questionnaire additionally provided questions within sub-sections which considered the areas including knowledge about educational policies and the rights of children with autism related to inclusive education, beliefs and outlooks on inclusive schooling for children with autism as well as their social and academic experiences in school including those specific to individual needs and feedback based on the same.

Data analysis

Interviews were audio recorded and transcribed verbatim. Thematic coding was utilised. Several themes common to both data sets emerged that provided answers to the research questions (Fig. 1).

Figure 1: Themes Emergent from the Research Study



The image is a visual representation of the themes that emerged out of the study specific to each of the research questions. Subthemes that emerged were collated into seven unique and dominant themes.

Findings and Discussion

Seven themes emerged from the study and are discussed in relation to each of the three research questions presented above.

What are the perspectives of parents of school-aged children with autism about inclusive schooling?

The parents whose children with autism were currently attending inclusive schools, believed this to provide the best opportunity for social interaction with typically developing peers. This guided their choice of an inclusive school for their child. Similar views have been expressed by parents in other studies on parents of children with special educational needs (Duhaney&Salend, 2000; Turnbull *et al.*, 2002; Elkins *et al.*, 2003; Leyser& Kirk, 2004; Waddington & Reed, 2006; Dimitrios *et al.*, 2008).

“If not schooling, where will his social interaction happen? He will not have any social interaction happening at all.”

Mother of a 11-year-old.

A majority of parents who participated in the questionnaire voiced the opinion that children with autism should attend schools practising inclusion, because this would offer exposure to real world situations and help with social integration in the future. A belief that, an inclusive school setting would provide opportunities for social interaction thus helping them to learn and adapt to situations which is a life skill was expressed by thirteen of the 15 sample parents. As stated by the parent to a 9-year-old boy with autism and additional diagnosis of ADHD;

“They should attend inclusive school as they have to live in real world and they have to handle all the challenges thrown at them so, inclusive school is best way to learn that...”

Most parents were also pragmatic and recognised that when children attend mainstream schools it was important that they were provided adequate supports for aiding positive outcomes which is in tune with the findings of Elkins *et al.* (2003) and Leyser& Kirk (2004). The other side of the debate was also expressed by one parent who felt that not all children with autism can be included in mainstream schools and only a special school would be able to provide the necessary support required for these children.

A couple of parents reasoned that inclusion would give typically developing peers the opportunities to be exposed to differences thereby paving the way to an inclusive society. However, some emphasised the need to sensitise peers as an important condition to this reasoning. According to the mother of a 10-year-old:

“For the NT (neurotypical) peers, it is an opportunity for them to interact and mix with kids with different abilities and expand their scope of interaction and thinking. It can be one of the stepping stones towards an inclusive society where all are accepted, welcomed and respected.”

The roles these parents envisage their children with autism as playing within the inclusive schooling system place them at the forefront of changing perspectives within the Indian context. Many other research studies report parental opinions similar to those mentioned above (Duhaney&Salend, 2000; Leyser& Kirk, 2004; Downing & Peckham-Hardin, 2007; Dimitrios *et al.*, 2008; Hill, 2009; Loreman *et al.*, 2009; De Boer *et al.*, 2010).

What are the actual experiences of the parents of school-aged children with autism with regard to inclusive schooling?

Most of the parents considered the happiness of their children as a crucial factor determining their decisions connected to inclusive schooling. Mala, a parent to a 11-year-old emphatically stated that it was her utmost priority while choosing schools.

“I would definitely look for his choice and his happiness. There were schools where he was not happy, even much more better functioning level schools were there, but he was not happy, so I had to forcefully pull him out of that school and give him a different school.”

Of the fifteen parents who responded to the questionnaire, eleven stated that they considered the happiness of their child when choosing and evaluating their experience of inclusive schooling. This is consistent with the findings of Parsons and Lewis (2010). However, the remaining parents stated that other influencing factors would also be considered during the process. Other parents were more realistic when they opined that the child’s comfort level was most important. The parents from Whitaker’s (2007) study too did not consider the child’s happiness the most important amongst the high priority areas identified in that study. One mother linked comfort level with the number of skills the child possesses to function in the inclusive school setting while his father questioned whether just being happy was enough?

The academic experiences related by the parents, showed variance between schools and even amongst children in the same school. Most parents stated that schools placed little emphasis on the academic aspects of schooling for these children. Some were in integrated provisions and opportunities to interact with typically developing peers were limited to non-academic classes.

Most of the parents who provided responses to the questionnaire stated that their children were provided opportunities to attend general education classrooms and learn with their typically developing peers and were also included in cultural and sporting programmes. Interactions with teachers and peers were generally stated to have been positive. While some of the schools allowed CWSN to attend general education classrooms for academics with shadow teachers for additional support, others provided remedial classes to address academic difficulties. A couple of parents specified that their child’s school had a special school attached to the mainstream and that their children were supported by the special school staff. Only nine parents stated that differentiation of the curriculum and assessments were the norm for their children and all of the parents in the study were insistent about the need for it. This was again consistent with the findings of other studies (Renty&Roeyers, 2006; Ravet, 2011; Reupert *et al.*, 2015). A few said that their children were restricted to being in provision specifically for CWSN attached to the mainstream school. The majority of the parents opined that regular school teachers lacked the training and awareness to support their children in the general education classrooms. Leyser and Kirk (2004) in their study reported similar findings. Even when they could participate in academic sessions, the greater responsibility of this lay with the special education teachers and parents. The quality of the educational services provided by the schools were rated moderate to excellent by 14 parents in terms of academic aspects and also on the basis of positive interactions with teachers and support staff experienced by the children. This is in agreement with other studies (Whitaker, 2007; Parsons *et al.*, 2009; Reupert *et al.*, 2015; Johansson, 2016; Majoko, 2017). There was one parent of an 8-year-old boy who disagreed to the interactions being positive saying that;

“Teachers never encourage the child.”

Parents agreed that schools had been flexible in meeting the individual needs of their child though one parent disagreed. Significantly, seven parents disagreed that the school had played a significant role in affirming the strengths and talents of their children. The majority of parents who participated in the questionnaire were mostly in agreement with the point that the schools their children attended had strong ethos of inclusion. A few of the parents disagreed though and one of the parents pointed out;

"There are disputes among the mainstream and special education teachers".

This did not present a picture of a positive inclusive atmosphere in the school. Another indication was that some of the schools did not have a documented inclusion policy or that parents did not know whether the school had one. Only nine parents agreed that the schools had in place practices connected to inclusion. Falkmer *et al.* (2015) too stress on the importance of schools having an ethos of inclusion in their review of literature.

These parents emphasised the positive and open attitude of the principal as the reason they were given this opportunity. However, the lack of training and awareness of general education teachers was also identified as areas of concern. This has also been highlighted by parents in other studies (Kasari *et al.*, 1999; Stoner & Angell, 2006; Waddington & Reed, 2006; Whitaker, 2007; Brewin *et al.*, 2008; Starr & Foy, 2012). The importance of the attitudes and initiatives of the school principal was emphasised by fourteen parents who participated in the questionnaire.

"In my opinion, commitment from the school management and principal is most important as the other factors (like training teachers etc) will automatically fall in place when the management is highly invested in inclusive education and treats it as a top priority"

With the exception of one, all mentioned that the principals were positive and encouraging in their attitudes towards children with autism.

How are the perspectives, expectations and actual experiences of parents interlinked?

Only six of the parent responders to the questionnaire agreed that they were satisfied with the way the school was collaborating with them about their child's schooling. Parents did express their opinion that parent-school collaboration should increase as parents know their children best and can provide valuable inputs. As the mother of a 12-year-old boy said;

"Since parents are the primary caretakers of the child, they would be able to give valuable insight for the proper direction of the inclusion process."

Others also stated the need for greater collaboration and transparency between schools and parents. This indicated an imbalance in the parent school relationship, with the school having an upper hand regarding all decisions. Many researchers have time and again reported parents voicing similar viewpoints (Ysselet *et al.*, 2007; Wong *et al.*, 2014). From the statements of other parents, it was clear that schools cooperated on their terms and that these children with autism may also be encountering exclusion at various levels; namely practical, intellectual and emotional; thereby reducing the experienced reality of inclusion. Of great significance is the fact that although parents expressed satisfaction with the inclusive process, they also voiced big changes they desired for the manner in which schools executed inclusion. The study thus revealed a conspicuous disparity between policy and practice in the context of inclusive education of children with autism in India. A similar disparity between policy and practice have also been reported by De Boer *et al.* (2010) in their review of literature as well as Leyser & Kirk (2004) based on the findings of the research studies included.

Conclusions

Most of the parents in this research study gave positive feedback about inclusion based on their own experiences. All who undertook the questionnaire agreed that inclusive schooling had had a positive impact on their children with autism.

The findings revealed a general though not unanimous level of satisfaction from parents. Significantly, parents were open, to conversing about both the positive and the negative aspects that they had encountered and indicated areas in which changes were desired. Parents believed that inclusive schooling offered their child a "stepping stone to social integration" and therefore was the option of choice. Significantly, parents were also particular about the happiness of the child being a guiding factor in the process of inclusive schooling. Another point of note was that, although most of the parents had a rights-based perspective, on which choices were made and decisions taken, in the course of their experience with inclusive schooling they accepted and adapted to partial or selective

inclusion, thus moving towards a more needs-based perspective. Parents also exhibited a leaning towards the social model of disability with greater emphasis not being laid on the child but on the school environment to adapt and change. This indicates the practical approach taken by parents in adopting an integrative approach to inclusive schooling, whereby both the needs and the rights of the child with autism are met. Crucial areas where parents were desirous of change were those of teacher knowledge and training in supporting children with autism and in the levels of parent-school collaboration. Parents desire greater emphasis on general education teachers being equipped to support children with autism in their classrooms rather than being dependent on special education teachers.

The parents in this study have contributed significantly to an understanding of the opportunities and challenges of providing an inclusive education for children on the autism spectrum. It is therefore appropriate to give the last word to one of these parents.

“A good inclusive school would be one where they would be open minded and have a willingness to help our children. Where they use all resources including the insight of parents to create a happy place where the children can feel safe to be themselves and find their own path in this world.”

- Sandhya (Vihaan's mother)

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