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SOCIAL INCLUSION OF CHILDREN DIAGNOSED WITHAUTISM SPECTRUM DISORDER IN INDIA: A LITERATURE REVIEW

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Abstract:

Autism Spectrum Disorder is a neurodevelopmental disorder defined by insufficiency in social communication and social interaction skills and restricted and repetitive patterns of behavior. The aim of this research was to analyze empirical studies on inclusion of

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children with Autism in India over the past 20 years and then propose recommendations for future research. A systematic process was used to conduct the review which included identifying the data source, assessing the quality of our studies, and drawing analysis of our findings. The result included different stakeholder's perspectives which were parents and teachers.

Keywords: social inclusion, children diagnosed with autism spectrum disorder, India

1. Introduction

Autism spectrum disorders (ASD) is defined by insufficiency in two main areas: lack of social communication skills and social interaction; restricted repetitive patterns of behaviour, interests and activities (American Psychiatric Publishing, 2013). The latest research (CDC 2014) detailed the incidence of ASD increasing to 1 out of 68 children. The lack of social skills is defined by irregular eye contact, attention deficit, eccentric speech patterns, trouble with both starting and sustaining conversations, absence of social critical thinking capacity, lack of compassion, and difficulties in deciphering gestures. (American Psychiatric Publishing, 1994). The children face difficulties in expanding their dialect and comprehending what is heard as well as problems in conveying their reasoning (Halfon N., Kuo A. A., 2013).

With the enactment of the UNCRPD (2006), the importance on educating children with Autism in the general classroom setting has proliferated exceedingly and has become an international movement. Inclusive Education (IE) is given mostly dependent on every one of the kids' entitlements to admittance to gain education close by with their companions paying little heed to their inability (S. Shahzadi, 2006).

For the past three decades, the notion of Inclusive Education (IE) has been approved. There are numerous studies taking place on the outcome of IE in relation to children with learning disabilities. Koegel et al. (2011) proved that IE among special needs children will enhance their social skills and progress further in their academics. According to Allen and Cowdery (2005), Inclusive Education (IE) enhances children's social skills.

2. Benefits of Social Inclusion

Frith (1991) proposed that the lack of social and communication skills may affect scholarly conduct which may confine interests, intellectual thinking, trouble with problem solving, paucity in organization skills and having difficulty deciphering information.

According to Lovaas and Smith (2000), children with ASD will benefit more if they are provided with appropriate educational and intervention settings at their young age. The focus on improving social skills in these children can be developed through these educational programmes and curriculums. Inclusive Education provides these benefits in the form or peer models and social opportunities. The peer model focuses on the children with ASD being benefited from the planned contact with their normal peers in the classroom.

To exhibit their thoughts, children diagnosed with autism demonstrate atypical / unusual behaviours such as being hostile or violent, having a temper or causing harm to themselves (Kulage K. M. et al., 2014). However, their propensity to convey themselves differs depending on their cognitive and communal growth (Baio J. et al., 2014. Thus, children diagnosed with autism are often perceived first by their social incompetency and a drawback in their communication skills.

During any leisure activity, children diagnosed with autism usually keep aloof or engrossed with themselves instead of being a part of the group or engaging in any play activity (Yaylaci F. et al., 2017). In fact, autistic children should be mingled with normal children in order to enhance educational, social learning and build on their emotional skills (Sturmey P. et al., 2014). Sawitree 2014, found that the learning of these children who are diagnosed with ASD is determined / impacted by the enhancement of their socialisation and communication skills with their friends. Moreover, a significant study done by Howlin & Goode (1998), asserted that children with ASD are insufficient in their social skill, which is one of the crucial factors needed in their future working environment and their quality of life.

These children with ASD who have been included in the same classroom as normal children will benefit from the planned contact with their non-disabled peers (J. B. Kupersmidt, 2004).

3. Aim of the Study

This research aims to review and analyse empirical studies on inclusion of children with Autism in India over the past 20 years and then propose recommendations for future research.

This study offers a compilation of initiatives taken for social inclusion of children diagnosed with autism spectrum disorder in India.

The results of this research will help to draw analysis on the strategies used to promote the social inclusion of these children into educational and other community settings.

4. Method

The purpose of this research was to analyse studies on social in clusion in children with autism spectrum disorder in India. A systematic process was used to conduct the review. Three steps were involved to carry on the process which included identifying the data source, a criterion to assess the quality of the studies and drawing analysis of our findings.

The first step was identifying the data base of studies and the authors have included SCOPUS and PubMed. The search keyword strings used were "social inclusion", "social skills", "autism spectrum disorder" and, "India", which appeared in the title, abstract, or keyword fields. The total number of identified articles from the searches of these databases was 29. Duplicate references were removed. After removing the duplicates, the count was reduced to 24 articles.

We excluded 13 articles by reading the title and abstracts of the study. The inclusion criteria included the following: must be an original study published between (2000-2021); must be published in the English language (non-English studies were excluded). The final number of articles in the analysis was 6.

4. Results

Narayan J. et al., (2005) conducted a study aiming to compile information on current education models like special schools, inclusive schools, home-based instruction, and units established by parent groups. The author's objective was to compile the information on the existing educational situation of children with ASD and analyse the feasibility for replication. In order to achieve the above objective, a questionnaire was sent to all special schools with follow up of one year and the information received was compiled and analysed. The authors found that the choice of model by parents depended on the child's level of functioning and parental aspirations. About 73% of the parents were eager to send their children to a suitable school, but dissatisfied with the existing facilities.

Another study by Awasthi and Avaramudhan (2019), in which authors used two short and three longitudinal case studies on children with autism to explore the meaning of inclusion and the barriers in the Indian context. A need for understanding inclusion was supported by authors in the context of home environment, education settings and large society. It was found that behaviours such as cooperation, reduction in impulsivity and communication were powerful enablers of inclusion across the different environments. Classrooms also provided a good setting for inclusive experience where fluency was built and appropriate classroom behaviours and specialised training for teachers were targeted.

A study conducted by Shah et al on 560 teachers working in government run schools in Ahmedabad, India was undertaken to determine the concerns of primary school teachers about the inclusion of students with disabilities. A two-part questionnaire was used which gathered personal and professional information of the teachers and the other was a 21 item Likert scale in Gujarati language. It was found that the teachers were least concerned about the lack of social acceptance of the students with disabilities in inclusive education classrooms. Certain parameters were taken into account in order to know why such unacceptability occurred and these were based on gender, background qualification in special education, teaching experience of these teachers and also the number of children with disabilities in a classroom (Shah et al., 2008).

In contrast, a study by Bhatnagar and Das (2014), conducted two focused group interviews with ten participants each and in addition to this, 20 semi structured interviews were also conducted. The respondents in this study were secondary school teachers working in schools in Delhi, selected from four administrative zones. The study focused on determining the attitude of the regular schoolteachers in Delhi towards the inclusion of students with disabilities. Views regarding facilitators of inclusive education were also explored and flexible qualitative data analysis was utilized. The findings showed that the teachers held a positive attitude towards the inclusion of these students with disabilities and also suggested improved infrastructure, changes in policy and provisions for institutional resources.

A study by Tiwari et al. (2015), focused on the identification and the articulation of teacher's perception and belief on providing educational services to students with disabilities in general classrooms. Semi-structured interviews of 15 teachers of public schools in Delhi were conducted. Constant comparative methods were used and the conclusions were drawn which included that different socio-cultural ideologies have impacted the education of children with disabilities and systematic barriers to education have made the teachers accept the concept of inclusion in theory. Barriers such social factors and lack of training opportunities have hindered the implementation of inclusive education.

Karanth and Chandhok (2013), conducted a study on 296 children through questionnaires which were collected through email, post, telephonic interviews and face to face interviews. The questionnaire covered three major areas which ranged from family's success on completing the recommendations of the early intervention (EI) program, issues faced in schooling and feedback on the EI program. The aim of the study was to follow up on the educational status of children diagnosed with ASD who had been enrolled for the early intervention program. The findings and recommendations concluded that early intervention helps in the enrolment and retention of children diagnosed with autism in mainstream schools.

Priyanka Nimbair et al., (2019) conducted a study which aimed at understanding peer victimization and its relationships to the self-esteem of the children having Mild Intellectual Disability and Borderline Intellectual Functioning issues. A sample of 40 children met the inclusion criteria. The results indicated that peer victimization was more in regular schools than in special schools.

A review study was done by Padmakumari P. et al., (2017) which focused on systematic examinations of different intervention practices which included improvement in social skills in ASD children practiced in India. The study collated 19 different papers published from 2000-2020 and evidence was presented in nine treatment categories. There was higher participation of males with the ages ranging from 1 year to 16 years.

Another study was done with an aim to explore the classroom practices of teachers influencing positive peer interaction between students with and without disabilities in public schools in Tamil Nadu, Chennai, India. The study also helped to determine the teachers attitudes towards students with disabilities and teacher's self-efficacy to foster

social inclusion. Data was collected was 93 teachers and 923 students in the form of questionnaires, interviews, and classroom observations. The results showed positive attitudes of the teachers towards inclusive education and high self-efficacy to support inclusive schooling (David, R., Kuyini, A. B., 2012).

Few studies also focused on the cross-culture differences to describe social inclusion for children with disabilities. One study done in Ladakh; India explored the meaning of inclusion for children with cognitive disabilities. It was stressed that families should receive as much attention as schools in terms of seeking solutions to maximise social inclusion once the children move back into their families after completing their education. It focused on the need to conceptualize inclusion locally (Koller, D., Pouesard, M. L., Rummens, J. A., 2017).

Sr	Author	Sample Size	Theme	Data Collection	Research	Inclusion
No.		-		Method	Approach	Setting
	Narayan J.,	Unknown		Questionnaire was	5	Special schools,
	Chakravarti S. N.,	Sample Size		sent to all special	1	inclusive schools,
	David J.,			schools	information on the	
	Kanniappan M.					instruction and
						units established by
					models and to find	parent groups.
					out the feasibility	
					for replication.	
2	Aravamudhan S.,	Participants (3	Barriers and	Case Study	The authors draw	
	Awasthi S.	boys and 2	facilitators		upon their clinical	
		girls) aged (4			expertise spanning	
		and 12 years) .			6 and 30 years	
					respectively, use	
					two short-term	Home environment,
					and three	educational
					longitudinal case	settings, and larger
					, ,	society.
					children with	
					autism to explore	
					the meaning of	
					inclusion,	
					enablers, and	
					barriers in the	
					Indian context.	
3	Karanth P.,	30	Early	Data was collected	A questionnaire	Communication
	Chandhok T .S.		intervention	through a	(Appendix 1)	DEALL program at
				questionnaire.	designed to obtain	Bangalore
				Contact modes -	information	
				email, post,	relevant to the	
				telephonic	child's progress	
				interviews, face-to-	after having	
				face interviews.	moved out of the	
					EI program,	
					focusing primarily	
					on issues related	
					to schooling was	
					designed.	

Table 1

Malvika Samnani, Sujata Shahi, Manish Samnani, Kanika Nanda, Mansi Srivastava, Pooja Singh SOCIAL INCLUSION OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER IN INDIA: A LITERATURE REVIEW

· · · · · · · · · · · · · · · · · · ·			
4		Two focus group	
		interviews were	
		conducted and	
		each group had	35 secondary
		ten participants. In	
		addition to the	administrative
0,			
Ajay Das 20 participants perspectives (c	· ·	focus group	zones of Delhi: East,
		interviews, 20	West, North and
		semi-structured	South.
		interviews were	
		conducted with	
		the teachers	
		selected from the	
		four	
		administrative	
		zones.	
5 Rina Shah, Ajay		Part 1 gathered	
Das, Ishwar Desai		information	
and Ashwini		relating to	
Tiwari A		personal	
		and professional	
		-	Working in
	5	the teachers.	government- run
soo teachers perspectives (s		Part 2 was a 21-	schools
			schools
		item Likert scale	
		titled	
		Concerns about	
		Inclusive	
		Education –	
		Gujarati.	
6 Ashwini Tiwari		15 semistructured	
A.,, Ajay Das, H	Hermeneutic	interviews of	
		public school	
μ μ		teachers in Delhi	
	5 0		Public school
1 1		Each interview,	teachers in Delhi
		lasting from 30	
m	nethod. (qualitative)		
		recorded and	
		transcribed.	
7 Nambiar P., 40 Peer Q	Questionnaire	The study utilized	The participants
Jangam K., victimization			were recruited from
Roopesh B. N., and self esteem		research design	the outpatient (OP)
Bhaskar A.		•	and inpatient (IP)
		1	services of Child
		40 children who	
			and Adolescent
		criteria.	Psychiatry
			Department of the
			research institution
			as well as from SS
			facilities.
			Children with ASD
8 Alexander, A. F. 19 Studies Different St	Studies published	Keview Stildy	
	-	Review Study	
Padmakumari, P., intervention fr	rom 2000 to 2020	5	in India
Padmakumari, P., intervention fr Padavan, I. D. practices that w	rom 2000 to 2020 vere selected for the	5	
Padmakumari, P., intervention fr Padavan, I. D. practices that w	rom 2000 to 2020 vere selected for the tudy. These studies	5	

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			social skills in ASD that is practiced in India	databases Ebsco, Proquest, PubMed, MEDLINE, science direct and Google Scholar.		
	David, R.,		Teacher's	Questionnaires,		Punchayat Union
	Kuyini, A.B.	collected from	perspectives	interviews and		Schools (public
		a sample of 93		classroom		schools).
		primary		observations	Survey	
		school			questionnaires	
		teachers and a			and participant	
		total of 923			observation along	
		students			with interviews	
10	Koller, D.,	Unknown	Cross Culture	The search was	Peer-reviewed	Ladakh, India
	Pouesard, M.L.,		Variables	conducted on a	original studies	
	Rummens, J.A.			biweekly basis from	published	
				December 2014 to	between January	
				March 2015, using	2004 and March	
				six databases	2015.	

5. Discussion

The above research gathered studies done on inclusion in the past 20 years. Most of the studies took a descriptive method approach using surveys whereas the others used a qualitative method.

In India there is a huge paucity of research for inclusion of children and rarity of information for inclusion of children with autism in mainstream schooling.

Three of the studies have focused on the perception of teachers on inclusion of children with disabilities. Some studies reflected a positive attitude while some still depicted a question on the whole idea of inclusion. Thus, these studies have found mixed results and there are concerns about teachers' attitudes and knowledge about inclusion. It is noteworthy that none of the studies have focused on the Autism population specifically but have included autism as part of other disabilities.

There is one study that has focused on barriers and facilitators of inclusion and has focused on children with autism. However, the authors have included only 5 children who cannot be a true representation of the autism population in a vast and populous country like India.

Only one study has done a follow up of children who received early intervention and found that children who receive therapy do retain in the schools and are able to adjust better.

6. Conclusion

The prevalence of Autism in India is 0.9% in the age group of children (0-15 years). Research shows that most students perform better when exposed towards the general education curriculum. Children do better academically when in inclusive settings and inclusion provides opportunities to develop a better understanding of relationships.

However, the review of literature states that there is a dearth of research on what has been done on implementation of inclusion of children with autism in India. Teachers' perception has been sought but no studies focused on perception of peers, and caregivers towards the concept of inclusion. One of the studies has studied various models that are availed by parents of children with Autism including mainstream schools and has categorically revealed that 73% parents were unsatisfied with the existing facilities.

It is needed that more research should be done and factors contributing to the understanding and implementation of inclusive education should be studied and more information should be added to the challenges and enablers.

It is also important to examine the effects of inclusion exclusively focusing on the autism population rather than as part of various disabilities.

Conflict of Interest Statement

The authors declare that there is no potential conflicts of interest with respect to the research, authorship and / or publication of this article.

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