



# Autism: Parenting Challenges and Child Care (in special context with Kanpur Nagar)

**Deepika Verma, Prof. (Dr) Rajiv Kumar**

PhD Research Scholar, Supervisor

Department of Sociology

Dayanand Brajendra Swaroop College, Kanpur

Affiliated with

Chhatrapati Shahu Ji Maharaj University, Kanpur-208024, Uttar Pradesh, India.

**Abstract-** Our constitution has given equal rights of living, health education and well-being to every individual of the society. A democratic welfare society is, where people live unprejudiced equal and free lives. Despite, people with physical and mental impairments, especially children are still facing lots of difficulties, to have a normal life due to lack of awareness, taboos, insufficient knowledge and their condition. Autism, being one of such mental impairment comes with the child since birth or develops during early ages of childhood. Child faces lots of neurological problems and gets difficulties in social interaction and communication.

Parents with autistic children always find themselves in challenging situations, when it comes about the schooling, teaching basic life skills, dealing with social stigmas and preparing the child for adult life. This paper highlights the parenting challenges faced by the parents of autistic children in the city of Kanpur Nagar. 50 parents are selected as respondents and after analyzing the situation it is concluded that they have very low level of awareness about autism and also the financial situation of most of the parents is a big challenge in dealing with the scenario. The social conditions also act as big hurdles. Many improvements such as training the parents, providing better healthcare facilities and taking initiatives to increase awareness levels by government and private sectors are required.

**Keywords-** Parenting challenges, autism, occupational therapies, social interaction.

## I. Introduction

The term 'Autism' was first coined by Swiss psychiatrist Eugen Bleuler in 1911 to describe a particular type of Schizophrenia, observed by him in children. In late 1970's autism was reconceptualized as a developmental disorder and with gradual experiments and medical developments, today's biological explanation of autism can be viewed as a spectrum range of behavioural disorders from lower to higher severity levels commonly known as Autism Spectrum Disorder (ASD). It is one of the five developmental disorders that come under the category of Pervasive Developmental Disorder which originates during childhood. It is one of the disability conditions among 21 categories classified under the Right of Persons with Disabilities Act 2016 by Government of India.

The autistic children suffer from many neurological problems and face mainly 3 types of difficulties which are lack of social interaction, difficulty in verbal and non- verbal communication and being engaged in repetitive behaviour, along with that other health issues like epilepsy, depression and anxiety. The children have different functioning patterns in their brain which led to different ways of learning, paying attention and

behaviour. As a result, they require special care and medical as well as social attention for their well-being and better life.

If we analyse the situation in India than according to the census 2011, the differently-abled population in India is 26.8 million i.e. 2.21%. Among which the disabled population in age group of 5-19 is 65.7 lakh in which 47.2% people are suffering from mental retardation. According to **Rehabilitation Council of India** 0.20% people of total population are suffering from Autism Spectrum Disorder and according to the Centre for Disease Control 1 in 166 children has ASD.

Genetic and environmental factors are considered responsible for the cause of autism. Children suffering from autism and their families face lots of difficulties since the day it is diagnosed. The lack of awareness is the major problem which leads to misinformation and misconceptions about this condition and as a result many children are misdiagnosed and mistreated. The children do not get proper education and correct medical facilities. The families face misbehaviour from the society. The parents suffer from psychological distress and frustration. Their financial condition and social status are also adversely affected. In this way, autism becomes a challenge for the parents and the children and they face a lot of challenges in parenting and education. Conditions are much more critical in cities like Kanpur where awareness level is very low and proper facilities are not available.

So, the main objective of this paper is to highlight the pedagogy and parenting challenges associated with autism and to provide few suggestive measures to ease the situation.

## II. Literature Review

- 1- Amritha Lakshmi Satheendranath, Alpana Joseph, Bhuvaneshwari B. (2024), Dr S R Chandrasekhar Institute of Speech and Hearing, Karnataka, India, in their research paper titled as “Parenting Styles and Parent-child Interactions in Autism Spectrum Disorders in India” have highlighted that parents of children with Autism in India use mixed parenting styles. Father use authoritarian and permissive parenting style while mother use authoritative parenting style. Behaviour of mother is more interactive.
- 2- Manushi Srivastava, Pradyumn Srivastava, Arun Kumar Dubey, Priya Srivastava (2024), Banaras Hindu University, in their research paper with title “A Narrative Review of Autism Spectrum Disorder in the Indian Context” have concluded that parents and family of the children with Autism go through very complex and negative experiences and face many challenges in their personal and social lives. An urgent need of services is required for the parents for their welfare. So that they can cope with the stress of parenting a child with Autism.
- 3- Prahbjot Malhi, Abhishek R. Shetty, Bhavneet Bharti, Lokesh Saini (2022), in their research paper titled as “Parenting a child with autism spectrum disorder: A qualitative study” have concluded that there are major obstacles in diagnosis of autism and there are many barriers and gaps in autism related services in the country. Parents face stress, behavioural challenges, negative attitude of society etc. they need more inclusive, supportive and family-centered model of care.
- 4- Gita Srikant and Swati Narayan (2020), WeCAN Resource Center for Autism, India, in their research paper titled as “Parental Attitude and Expectations in Raising a child with Autism Spectrum Disorder in India” studied parents of 28 autistic children in the city of Chennai and concluded that there is an urgent need for providing a proper understanding about autism and more scientific innovations are required. Better educational and therapeutic interventions are required for autistic children and their families.

## III. Parenting Challenges

Autism is a spectrum disorder because the severity of the symptoms may range from mild difficulties in social interaction or learning to complex mix of unusual behaviours that affect every day functioning. Every child with autism is unique, no two children on autism spectrum possess the same skills or challenges. That’s why, when it comes to autism and education there is no-one size-fits-all approach. Autism is very challenging and stressful experience for the family, especially the parents. The most prominent parenting challenges are-

1. Difficulty in understanding that child is autistic due to lack of awareness and diagnostic facilities.
2. Lack of interventional strategies as each child with autism is different and require a different strategy.
3. Difficulty in finding special schools with well-trained educators for autistic children.
4. The special schools are very costly and most of the parents cannot afford them.

5. Children face many sensory challenges during school hours like unnecessary noises, fluorescent lights, extreme smells and yelling children. For children with autism, the sensory stimuli can be overwhelming, triggering extreme anxiety and autistic behaviour.
6. Children sometime need sudden medical attention due to above reasons but school lacks the medical staff to help in this situation.
7. A child on the spectrum often needs a combination of occupational therapy, speech therapy, special education and structured training. Coordinating the therapies and ensuring that child is receiving what is needed, is a huge challenge for the family.
8. As autistic children are socially restricted, finding empathetic playmates who can help the child with autism adapt to different situations, often becomes an uphill task.
9. Parents are misguided by the elders in the family. They offer excuses such as, “He is just a child”, “Her father also had a delayed speech” and so on.
10. In several cases owing to superstitious beliefs surrounding mental health, many parents end up being cut off from their families. They are begged down by astrological practices and religious traditions that delay seeking scientific and effective therapies.

#### IV. Research Methodology

Research Design- Exploratory Research Design has been adopted in this research paper.

Universe- Three special schools running in Kanpur Nagar with the strength of 182 children, are selected as the universe.

Sampling Technique- Purposive Sampling has been taken as a sampling method to collect the samples.

Sampling size- 50 Parents of autistic children has been selected as respondents.

Data collection method- Primary Data has been collected with the help of semi-structured interviews and secondary data has been collected through internet websites, books, articles, government websites.

#### V. Outcomes

1. 42 out of 50 parents (84%) accepted that they did not understand that their child had autism because they were not aware of it.
2. 36 out of 50 parents (72%) confirmed that Kanpur city does not provide correct diagnostic facilities. They had to visit different cities like Lucknow, Delhi, Chennai etc, for their child’s treatment and correct diagnosis. The facilities available in Kanpur are very few and bit costly.
3. 44 out of 50 parents (88%) agreed that it was very challenging for them to find suitable school for their children as special schools are very few in number in Kanpur city.
4. 36 out of 50 parents (72%) accepted that they still think that school should have more well-trained educators as their child’s development and growth is very slow.
5. 38 out of 50 parents (76%) have told that on sudden anxiety, panic attacks or epilepsy attacks, they were called from school and the child was sent back home. The school seems lacking proper medical attention in emergency situations like this.
6. 26 out of 50 parents’ (52%) financial status is average so they are facing huge financial burdens in their child’s treatment and education.
7. Only 32 out of 50 parents (64%) can afford therapies other than schooling as they are very costly.
8. 44 out of 50 parents (88%) told that the child remains secluded after school as other children who are normal, do not want to play with the child as they are either scared or are unable to figure out how to behave with the child.
9. 34 out of 50 parents (68%) agreed that they take their children to other cities for occupational therapies, speech therapies and other treatments required for the child.
10. 36 out of 50 parents (72%) informed that they are unable to find the government centres which are meant for children with special need in the city and they do not know how to get government benefits and subsidies.
11. 28 out 50 parents (56%) find it very difficult to figure out how to deal with child’s behaviour and how to teach and train him or her.

12. 42 out of 50 parents (84%) agreed that their elders and other family members misguided them about their child's situation due to lack of knowledge which resulted in delay of the treatment.
13. 32 out of 50 parents (64%) accepted that due lack of awareness, the child was considered bad omen and the family of the child was cut off from society.
14. 40 out 50 parents (80%) accepted that they were forced to perform astrological practices and religious traditions to cure the child.

## VI. Conclusions and Suggestions

The following conclusions are derived after analysing the outcomes and few suggestive measures are-

1. Kanpur city provides very selective options for the parents about diagnostic facilities, schooling and about the treatment options of autistic children.
2. The schools which are running in the city for special children though promises, availing trained educators, well equipped classrooms and all the facilities required. Yet, practically they are some how lagging behind and needs to develop the infrastructure in more advanced manner.
3. Sunday play schools should be organised in special schools and other schools should be invited to collaborate. In this way normal children and autistic children can play and interact.
4. More attention is needed on government level to develop more advanced infrastructure, better hospitals, cheaper schools and better and cost-effective treatment facilities.
5. The awareness level about the autism is very low. Common people should be made aware of it through awareness campaigns and media highlights.
6. Social media funding is a good option to aid those parents who are financially struggling.
7. NGOs participation should be encouraged and more people should volunteer to help autistic children and their families in any way possible.
8. Social stigma is very high regarding mental disorders and can be curbed by educating people more and more about them.
9. Advanced training centre need to be developed in the city with the help of government subsidies and public funding so that the parents and teachers can be trained in the more advanced way.
10. The government schemes and programs should be launched properly and required to be monitored by government authorities in proper manner. In this way more and more people can be benefitted from them.

Autistic children and their families are part of society as we are. They just some special needs other than common people. Autism is not a taboo; it is only a condition that can be controlled if the correct treatment is available for it. The child has great potential, if explored correctly. So, it is our duty as a society to hold hands together and support the families and the children. It is our duty to create a friendly environment for them, to make them feel normal and include them as an important part of society. In this way they can become self-independent and live a better life.

## References

1. Satheendranath Amritha Lakshmi, Joseph Alphonsa, B. Bhuvanewari (2024). Parenting Styles and Parent-child Interactions in Autism Spectrum Disorders in India; *The International Journal of Indian Psychology*; 12(2), 2461-2475. e-ISSN 2348-5396, p-ISSN 2349-3429.  
DOI: 10.25215/1202.213. <https://www.ijip.in>
2. Srivastava Manushi, Srivastava Pradyumn, Dubey Arun Kumar, Srivastava Priya (2024). A Narrative Review of Autism Spectrum Disorder in the Indian Context; *Journal of Indian Association for Child and Adolescent Mental Health*; 19(4).  
<https://doi.org/10.1177/09731342231223589>

3. Malhi Prabhjot, Shetty Abhishek R., Bharti Bhavneet, Saini Lokesh (2022). Parenting a child with autism spectrum disorder: A qualitative study; *Indian J. Public Health*; 66(2), 121-127. DOI: 10.4103/ijph.ijph\_1779\_21
4. Srikant Gita, Narayan Swati (2020) Parental Attitude and expectations in Raising a Child with Autism Spectrum Disorder in India; *IOSR Journal of Humanities and Social Science*; 25(8), 50-56. e-ISSN 2279-0837, p-ISSN 2279-0845. DOI: 10.9790/0837-2508015056.
5. [www.researchgate.net](http://www.researchgate.net)
6. <https://pubmed.ncbi.nlm.nih.gov>
7. <https://www.autismparentingmagazine.com>
8. [www.wikipedia.com](http://www.wikipedia.com)