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UNVEILING AND GENERATING AWARENESS ABOUT AUTISM IN PUNE DISTRICT IN INDIA

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Abstract: Autism Spectrum Disorder (ASD) It is a developmental disorder that impairs the ability to communicate and interact. Children and adults on the spectrum find difficulty in communication, play, understanding emotions, unfamiliar situations and change in routine. The prevalence of autism has been increasing over the past few years. 1 in 68 children in India are autistic. As per World Health Organization, Care for autistics needs to be accompanied by actions at community and societal levels for greater accessibility, inclusivity and support. Scientifically backed sustained early interventions can have a positive impact on the quality of life of the individual and their families. A general public awareness in an urban setup in Pune was assessed and information about autism was shared in direct interviews and awareness sessions. The survey included testing the general awareness, signs and symptoms, knowledge about care and inclusion, reducing stigma and debunking common myths about autism and understanding if their school or office environment was inclusive for autism. Coefficient of Autism Awareness was calculated, it revealed that the awareness does not have any statistical correlation with age, education, income, profession. Awareness should be targeted at all levels of society, regardless of demographic factors. This inclusive approach is essential to ensure that information about autism reaches individuals across diverse backgrounds and demographics. Inclusive Education is deemed to be best foot forward for sustainability. However, the diverse individual needs of the population have to be understood in depth. Autism being one of key diversities impacting education of many, needs more awareness from policy makers to implementers.

Keywords: Autism Spectrum Disorder (ASD), Autism awareness, disability inclusion, Coefficient of Autism Awareness (CoA), inclusive education, awareness survey

Introduction

Autism Spectrum Disorder (ASD) It is a developmental disorder that impairs the ability to communicate and interact. Children and adults on the spectrum find difficulty in communication, play, understanding emotions, unfamiliar situations and change in routine. Some autistic people can live independently while some need care for their entire life. The cognitive abilities of autistic people can vary from very poor to being gifted where some of them depict very high levels of intelligence (DSM, 2013). The prevalence of autism has been increasing over the past few years worldwide and India is not behind. India included Autism as a recognized form of disability in the RPWD Act 2016. Efforts are being made to identify and register all individuals with disabilities under the Unique Disability Identity (UDID) scheme of the central government.

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Awareness about Autism

The need to make the community sensitive and inclusive about autism requires many steps beginning with creating awareness to aligning policies in order to meet a vision aimed at being inclusive. Awareness has multiple dimensions. It cannot be done in silos.

Creating a truly inclusive society necessitates a multifaceted approach that begins with raising awareness and extends to policy alignment. Awareness efforts must encompass various sectors, including families, educational institutions, public service providers, healthcare providers, and employers and policy makers. In India, it appears to be that child health programs focus mainly on child survival issues. Very little attention is paid to developmental disabilities at policy and implementation level and as a result, budget allocations and human resource deployment are directed away from these programs (Raina, 2019).

It was observed that a correct diagnosis had been made in only 5.8% of children prior to referral (Juneja, 2005). A descriptive study conducted at an urban tertiary care center in India reported majority of autistic children from middle class. Estimation of true prevalence of ASD in India is going to improve policies on developmental disabilities (Zeidan, 2022).

In contrast, findings from Saudi Arabia reported most of the children diagnosed with autism belonged to families of low socioeconomic standards with unsatisfactory income (Omolayo, 2020). Evidence suggests an inverse correlation between SES and mental health; however, this causation is based on longitudinal studies (Alsehemi, 2017).

In a worldwide study on prevalence of Autism it was reported that approximately 1/100 children are diagnosed with autism spectrum disorder around the world. Prevalence estimates increased over time and varied greatly within and across sociodemographic groups. These findings reflect changes in the definition of autism and differences in the methodology and contexts of prevalence studies (Zeidan, 2022)

Data collected by the ADDM Network in 2020 show that ASD continues to increase over previous years' numbers. About 1 in 36 8-year-old children living in ADDM Network sites were identified with ASD in 2020, based on tracking in 11 communities across the United States. This number is higher than 2018, which was 1 in 44 (ADDM Report, 2020). In an awareness study conducted on primary school teachers, 95.7% of the teachers were aware of autism. But in reality only 21% had adequate knowledge of autism (Shetty, 2014).

Awareness is crucial for combating stigma and discrimination Despite efforts made in recent years, stereotypes and misconceptions persist, leading to social isolation, bullying, and exclusion. By promoting positive portrayals of autism in the media, and fostering inclusive communities, we can create a more accepting and supportive environment.

A similar study was also conducted with Speech-language pathologists (SLPs), (these are therapists who work with children having speech challenge and are significant team members in the identification, assessment, and rehabilitation of children with autism. The study results indicate that SLPs practicing in India show average and below average scores on a questionnaire assessing

knowledge and beliefs regarding autism. The study findings have implications towards developing improved training and course structure related to assessment and intervention of children with autism for SLPs practicing in India (Mendonsa, 2018).

In a recent UK study published in 2024, it was revealed that since the COVID-19 pandemic, there has been a 306% increase in the number of children waiting for an autism assessment (Longfield, 2024).

This study aims to address the critical need for enhanced autism awareness through the development of a comprehensive awareness tool. By assessing and generating awareness among frontline workers across various sectors, the study seeks to foster inclusion and support for individuals with autism

One of the primary objectives of autism awareness is to promote early identification and intervention, as research has shown that early diagnosis and access to appropriate interventions can significantly improve outcomes for individuals with ASD. By equipping parents, caregivers, educators, and healthcare professionals with the knowledge and resources to recognize the early signs of autism, we can ensure that children receive the support they need to reach their full potential.

Objectives of the Study

1. Assessing general awareness and understanding of autism spectrum disorder, including its signs and symptoms

2. Introducing the Coefficient of Autism Awareness (CoA) on a 15-point scale to quantify awareness levels

3. Exploring correlations between the Coefficient of Awareness and demographic parameters such as age, education, income, profession, and prevalence

By clarifying the nuances of autism and fostering informed action, this study will contribute to the creation of a more informed and hence supportive environment for individuals with autism. We aim to provide insights and recommendations for advancing efforts to promote awareness about autism. From campaigns and public awareness events to community-based initiatives and advocacy efforts, there are myriad ways in which individuals, organizations, and policymakers can contribute to the promotion of autism awareness.

Study Design

A comprehensive survey questionnaire was designed to address each of the three objectives listed for the study.

A focussed questionnaire was designed to understand the knowledge, resources and prevalence of ASD in general public. The original version was designed in English and tested on 10 participants. After incorporating the corrections, the questionnaire was translated in Marathi to include teachers in government pre-school education setup.

The tool comprised of four sections, two sections were interrogative to check know how and two sections were informative to create awareness. It comprised of 6 questions about demographic data and 13 questions about Autism awareness.

This study adopts a mixed-methods approach, combining face-to-face and online survey administration, to assess awareness levels regarding autism spectrum disorder. The use of both modes of survey administration enhances accessibility and inclusivity, catering to diverse participant preferences and logistical considerations.

Table 1: Questionnaire

No.	Question	% age of correct answers	Degree of Awareness
Q1	Are you familiar with Autism?	58%	Basic Knowledge
Q2	What are the typical symptoms of autism? (8 sub questions)	16% got more than 50% Correct	Better Understanding
Awareness Message 1	It is a developmental disorder that impairs the ability to communicate and interact. Autistics find difficulty in communication, playing with others, understanding others' emotions, bright lights, high pitch sounds, unfamiliar situations and change in routine. Autism is a spectrum. Everybody with autism is different. Some autistic people hardly need support. Others need support all the time. Some autistic people have average or above average intelligence.	Information to the participant	
Q3	Is autism contagious?	91%	Basic Knowledge
Q4	Is autism caused because of parenting problems?	73%	Basic Knowledge
Q5	Can Autism be cured?	34%	Better Understanding
Q6	Can a autistic child attend regular schooling?	57%	Better Understanding
Q7	Do you think an autistic individual can do the same professional work as you are doing?	44%	Better Understanding
Q8	Are you aware of any specific center in your city which helps autistic children?	35%	Better Understanding
Q9	Do you know of any regular school which allows autistic children in their school (Inclusive School)?	31%	Better Understanding
Q10	Does your school or office have any autistic people?	35%	Prevalence of Autism
Q11	Does your family have an autistic member?	10%	Prevalence of Autism
Q12	Does your neighbourhood have an autistic individual?	22%	Prevalence of Autism
Q13	If you meet someone an autistic person, how would you interact with them?	Qualitative Input	Better Understanding

Awareness Message 2	Autism is not an illness or a disease. The autistic brain works in a different way from other people. Autism is something you are born with. It is not a disease and hence there are no treatments or a "cure". But some people need support to help them with certain things. Like everyone else, autistic people have things they're good at as well as things they struggle with. Being autistic does not mean you can never make friends, have relationships or get a job. But you might need extra help with these things. Nobody knows the cause of autism. Thank You!!		Information to the participant

The Coefficient of Awareness (CoA) is computed based on participants' responses to the questionnaire items. The CoA serves as the dependent variable, reflecting the overall level of awareness among the participants

- Null Hypothesis – Education, Age, Income level, Profession does not have any significance on the awareness level about autism spectrum disorder

- Alternative Hypothesis – Education, Age, Gender, Income level or Profession influences the awareness level about autism spectrum disorder

Methodology

A stratified sampling technique is employed to ensure representative participant selection across demographic categories. The study participants encompass people from various professions, age groups, gender identities, educational backgrounds, and income levels. Specific emphasis is placed on having participants from Pune district in India, with a targeted inclusion of teachers from government preschools. This enabled the inclusion of participants from diverse backgrounds while maintaining proportional representation within each stratum. This diversified participant profile ensured comprehensive insights into awareness levels across different demographic segments.

Face to Face interviews were conducted by trained interviewers to standardize the procedure and ensure consistency and reliability in data collection. For online mode, it allowed flexible participation. Clear instructions were provided about the objective of the study to facilitate accurate completion.

Table 2: Sample details

Mode	Count
Face to Face	146 (29%)
Online	355 (71%)
Total	**500**

Gender	Count
Male	153 (30%)
Female	347 (70%)
Total	**500**

City	Count
Pune	264 (53%)
Metro City	116 (23%)
Secondary City	104 (21%)
International	16 (3%)
Total	**500**

Income Pm	Count
Not Revealed	49 (10%)
Less than 10K	57 (11%)
11K to 25K	17(3%)
25K to 50K	37 (7%)
50k to 1 Lac	136(27%)
Above 1 Lac	204 (41%)
Total	**500**

Education	Count
10th	28 (6%)
12th	36(7%)
Undergraduate	154 (31%)
Graduate	97 (19%)
Post graduate	162(32%)
Doctorate	8 (2%)
Illiterate	15 (3%)
Total	**500**

Age	Count
14 to 21	155 (31%)
22 to 30	51 (10%)
31 to 40	54 (11%)
Above 41	240 (48%)
Total	**500**

Profession	Count
Business	32 (6%)
Corporate	31 (6%)
Engineering	30 (6%)
Government	16 (3%)
Govt. Education	97 (19%)
Healthcare	44 (9%)
Homemaker	30 (6%)
IT	80(16%)
Labourers	5 (1%)
Private	94 (19%)
Social	10 (2%)
Allied	31 (6%)
Grand Total	**500**

Normal Distribution for the CoA was plotted. 10% of the participants had a CoA level below 25% of the maximum score and 11% had above 75% of the maximum score.

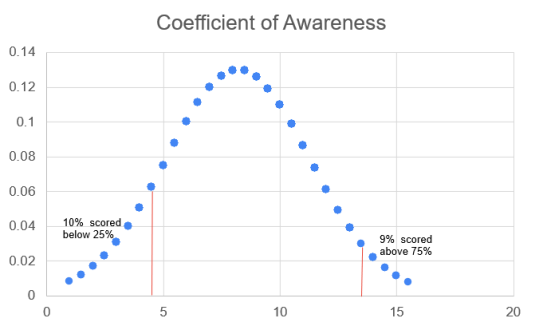

Figure 1: Normal Distribution of CoA

The survey also included awareness information to the participant at two stages in the questionnaire. 291 (58%) of the participants responded to having familiarity with Autism. However, only 82 (22%) of these scored higher on the CoA. Correlation and regression analyses, were performed to explore relationships between demographic variables (gender, age, education, city, income, profession) and Coefficient of Awareness (CoA). ANOVA test was administered on the data to test the null hypothesis.

Results

Table 3: Karl Pearson Correlation of CoA

Karl Pearson Correlation of CoA					
Gender	**Age**	**City**	**Education**	**Profession**	**Income**
-0.100	-0.097	-0.103	0.208	0.105	0.150
Insignificant	Insignificant	InSignificant	Slightly Significant	Slightly Significant	Slightly Significant

The correlation coefficient between CoA and gender, age, city, indicates a weak negative correlation. The p-value suggests that this correlation is statistically insignificant, implying that there is no significant relationship between gender and awareness levels. The correlation with Education, Income and Profession is moderately positive The p-value suggests that this correlation is slightly significant, implying that there is some evidence to suggest a relationship between education level and awareness levels, although it is not very strong. To confirm this further analysis of variance (ANOVA) was conducted to assess the relationship between the variables under investigation.

Table 4: Correlation Coefficient

Coefficient of Determination Rsquared					
Gender	**Age**	**City**	**Education**	**Profession**	**Income**
0.0100	0.0095	0.0107	0.0433	0.0110	0.0226

Table 5: ANOVA – CoA and Education

ANOVA: Single Factor - CoA and Education						
SUMMARY						
Groups	Count	Sum	Average	Variance		
Education D4	500	1851	3.702	1.280		
Awareness score (AS)	500	3862.5	7.725	7.962		
ANOVA						
Source of Variation	SS	df	MS	F	P-value	F crit
Between Groups	4046.1322	1	4046.132	875.639	1.16E-138	3.851
Within Groups	4611.5355	998	4.621			

Table 6: ANOVA – CoA and Income

ANOVA - CoA and Income						
SUMMARY						
Groups	Count	Sum	Average	Variance		
CoA	500	3862.5	7.725	7.962		
Income	500	1763	3.526	3.011		
ANOVA						
Source of Variation	SS	df	MS	F	P-value	F crit
Between Groups	4407.90025	1	4407.900	803.398	3.9265E-130	3.851
Within Groups	5475.5995	998	5.487			

Table 7: ANOVA – CoA and Profession

ANOVA - CoA and Profession						
SUMMARY						
Groups	Count	Sum	Average	Variance		
CoA	500	3862.5	7.725	7.962		
Profession	499	3310	6.633	9.614		
ANOVA						
Source of Variation	SS	df	MS	F	P-value	F crit
Between Groups	297.672	1	297.672	33.876	7.9E-09	3.851
Within Groups	8760.825	997	8.787			

Limitations and Further Scope

This research has been primary conducted in urban setup in Pune, India and does not cover the rural population. Although the demographic factors within an urban setup do not seem to influence the Coefficient of Awareness, further study can be conducted to cover the rural segment also.

Conclusion

The p-values obtained from the ANOVA for all the independent variables were found to be significantly less than the common threshold of 0.05. This indicates that there is a statistically significant relationship between the independent variables (age, education, income, profession) and the dependent variable CoA (awareness level) about autism.

The coefficient of determination (R-squared) was found to be significantly low, suggesting that only a small proportion of the variance in the coefficient of awareness can be explained by the independent variables.

Therefore, based on the statistical analysis, the null hypothesis is accepted. This means that there is no significant influence of age, education, income, or profession on awareness levels about autism. It can be concluded that awareness efforts about autism should be targeted at all levels of society, regardless of demographic factors. This inclusive approach to awareness initiatives is essential to ensure that information about autism reaches individuals across diverse backgrounds and demographics.

Recommendations

- Comprehensive, coordinated and sustained efforts are required towards creating widespread awareness amongst all, including medical fraternity, school teachers and communities at large.

- Everyone should have equitable access to healthcare facilities, educational needs, social engagement and opportunities to become contributing members of the society.

- There is a need for commitment to support care givers and capacity building of healthcare workers and teachers with holistic coping strategies.

- Knowledge to enable Early identification and intervention can help improve behavior management.

References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). American Psychiatric Publishing.

Alsehemi, M. A., Abousaadah, M. M., et al. (2017). Public awareness of autism spectrum disorder.

Centers for Disease Control and Prevention. (2020). Higher autism prevalence and COVID-19 disruptions – ADDM report.

Kingdon, C., & Longfield, A. (2024). An evidence-based plan for addressing the autism assessment and support crisis. Centre for Young Lives & Royal College of Paediatrics and Child Health.

Lebenhagen, C. (2022). Autistic students' views on meaningful inclusion: A Canadian perspective.

Mendonsa, L. E., & Tiwari, S. (2018). A survey of knowledge and beliefs regarding autism in speech-language pathologists in India.

Juneja, M., Mukherjee, S. B., & Sharma, S. (2005). A descriptive hospital-based study of children with autism. Indian Pediatrics, 42(5), 453–458.

Omolayo, B. (2020). Knowledge and awareness of autism spectrum disorder among teachers in Ekiti State, Nigeria.

Raina, S. K., Chander, V., Bhardwaj, A. K., et al. (2019). Prevalence of autism spectrum disorder among rural, urban, and tribal children (1–10 years of age).

Shetty, A., & Rai, B. S. (2014). Awareness and knowledge of autism spectrum disorders among primary school teachers in India.

United Nations. (2018). United Nations disability inclusion strategy.

Zeidan, J., Fombonne, E., Scorah, J., et al. (2022). Global prevalence of autism: A systematic review update.

Autism incidence and spatial analysis in more than 7 million pupils in English schools: A retrospective, longitudinal, school registry study. (2022). The Lancet.