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Starting Early: The Benefits of a Parent-Centered Approach Intervention to Autism

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Abstract: The provision of psychological and social care is regarded as the cornerstone of autism therapy in India. Despite this, the delayed diagnosis of autism, often not occurring until children reach the age of four, results in missed opportunities for early intervention, potentially hindering overall development. Additionally, the developmental diversity of autism spectrum disorder (ASD) has led to a scarcity of systematic, evidence-based research on the efficacy of various therapies. This study aims to address these gaps by implementing a holistic intervention designed to evaluate and enhance children's development across multiple domains, including fine and gross motor skills, adaptive skills, cognitive development, social communication, and social development. Our proposed intervention utilizes a randomized design, comparing outcomes between a group receiving standard care and a group receiving the experimental treatment, with parents serving as the primary communicators for their children. We hypothesize that this approach will facilitate early detection, prompt care, and improved outcomes for children with autism in India.

Methods: The study involved enhancing standard care with daily four-hour sessions for parents over six days, with the seventh day reserved for home activities, focusing on the holistic development of their children. Seventy children at risk for ASD, as indicated by the Modified Checklist for Autism in Toddlers Revised, With Follow-Up (M-CHAT-R/F)™, were randomly assigned to either the standard care group or the experimental group. Stratification was based on age and baseline data. Outcomes were assessed using standardized instruments at four intervals over a two-month period.

Results: The study reported no dropouts, and both groups received consistent routine care throughout the research period. The experimental group demonstrated statistically significant improvements in all domains assessed by the Assessment, Evaluation, and Programming System for Infants and Children (AEPS®-3), including fine and gross motor skills, adaptive skills, cognitive development, social communication, and social development.

Conclusion: The Pre-Post Comparative Design utilizing randomization proved feasible and was well-received by parents. The findings indicate substantial additional benefits of the holistic intervention for children under the age of two, compared to conventional care. This study advocates for further research with larger sample sizes and extended durations to corroborate these findings and supports the implementation of similar randomized controlled trials in this field.

Keywords: Autism Spectrum Disorder (ASD), Early Intervention, Holistic Development, Randomized Controlled Trial, Parent Engagement, Assessment, Evaluation, and Programming System for Infants and Children (AEPS®-3), Modified Checklist for Autism in Toddlers Revised, With Follow-Up (M-CHAT-R/F)™

Introduction:

Since its discovery more than half a century ago, autism has been an intriguing topic for inquiry and academic investigation. Over time, related developmental illnesses such as autistic disorder, Asperger's syndrome [1], pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett's disorder [2] were identified, culminating in the broader diagnosis of Autism Spectrum Disorder (ASD). ASD is characterized by significant deficits in social, behavioral, linguistic, and creative development, along with repetitive and stereotyped patterns of conduct and interests [3]. Individuals with ASD also tend to have a narrow range of interests and behaviors. The onset of these symptoms typically occurs within the first two years of a child's life.

In terms of prevalence, India is ranked 21st globally, with 88.50 incidences of autism per 10,000 children. This contrasts with countries like Qatar and the United Arab Emirates, which have the highest prevalence rates, at 151.20 and 112.40 cases per 10,000 children [4], respectively. The prevalence of autism in India is like the global trend, where recent data shows a significant increase. For instance, as per World Population Review- 2021, in the United States, the prevalence of ASD increased by 10% from 2014 to 2016, with about 1 in 54 children identified with ASD by age eight [5].

The concept of early intervention offers various strategies, both comprehensive and targeted, to assist children in preparing for their roles in society. However, many of these interventions tend to focus on a limited number of developmental aspects within a specific timeframe, often overlooking the interconnections between different developmental domains. This narrow focus can impede a child's overall growth, as children at risk for ASD typically face challenges across multiple transdisciplinary domains. Therefore, a comprehensive treatment strategy that addresses all aspects of development is crucial.

A complete treatment program for children at risk for ASD is essential due to their multidimensional developmental needs. The Assessment, Evaluation, and Programming System (AEPS®) is a comprehensive intervention tool designed to cover six broad developmental areas: fine motor, gross motor, adaptive, cognitive, social communication, and social development. This system benefits from measuring functional skills, using observations, involving family members, monitoring performance, and allowing for adaptations and modifications, thereby supporting the comprehensive development of children across all areas [6].

Despite the recognized need for a holistic approach, many studies have failed to adopt this perspective. To address this gap, our research aimed to conduct an all-encompassing evaluation and assessment of children's development across multiple domains simultaneously. By doing so, we sought to gain a deeper understanding of the interrelationships among various aspects of child growth and to provide a more effective intervention strategy for children at risk for ASD.

Methodology and Materials:

This quasi-experimental study was conducted at a government autism training center in Trivandrum city, Kerala, India, employing a quantitative research methodology. The objective was to include all children aged 2 to 3 years within the Trivandrum District who were at risk of developing Autism Spectrum Disorder (ASD). The sample consisted of seventy children, both male and female, from nuclear families of various religious backgrounds. Participants were selected randomly from several child developmental delay detection centers. Parents of children exhibiting abnormal behavior were recruited, and those who volunteered completed a demographic questionnaire. This questionnaire collected information on the child's name, age, gender, religion, the parents' level of knowledge about ASD, and their participation in early intervention programs for ASD.

Children were initially assessed using a standardized diagnostic instrument to determine their risk for ASD. A pilot study was conducted over twenty days to validate the reliability and practicality of this diagnostic tool. The results confirmed the instrument's feasibility, reliability, and validity for the main study.

Seventy participants were then randomly assigned into two equal groups of 35 each, using a random number generator: an experimental group and a control group. The experimental group received the research intervention based on the Assessment, Evaluation, and Programming System (AEPS®-3), in addition to the regular care provided by the center. The intervention spanned six days per week, with one day off, over an eight-month period. The control group received only the standard therapy offered by the training center.

The AEPS®-3 is a comprehensive intervention tool that addresses six key developmental domains: fine motor, gross motor, adaptive, cognitive, social communication, and social development. It measures functional skills through observations, involves family members in the therapeutic process, monitors performance, and allows for necessary adaptations and modifications, thereby fostering holistic development in children with ASD.

Outcomes were evaluated bi-monthly using standardized instruments, identical to those used in the initial assessment, to measure progress in the six developmental domains. This consistent assessment schedule ensured rigorous data collection and allowed for a robust comparison of developmental gains between the experimental and control groups. Statistical analyses were performed to determine the effectiveness of the intervention in improving developmental outcomes for children at risk of ASD.

Data Analysis:

To evaluate the empirical evidence and explore differences based on the study's aims and hypotheses, both descriptive and inferential statistics were employed. Categorical variables were summarized using frequency and percentage. For quantitative variables, the mean and standard deviation (SD) were reported for normally distributed data, while the median

and interquartile range (IQR) were used for data that were not normally distributed.

To ensure the experimental and control groups were comparable, a Chi-square test was conducted to assess significant differences in the baseline frequency distribution of demographic characteristics.

The efficacy of the intervention across various skill domains and overall skill levels was evaluated using a two-way repeated measures mixed ANOVA. The Bonferroni correction was applied to adjust for Type-I error due to multiple comparisons.

Further analyses included independent sample t-tests and ANOVA to investigate significant relationships between the overall development score, scores in different developmental domains, and demographic factors, assuming normal distribution of data. For non-normally distributed data, the Mann-Whitney U test and the Kruskal-Wallis test were utilized.

All statistical analyses were conducted using SPSS and EZR software packages. A p-value of less than 0.05 was considered statistically significant.

Discussion of Results:

The American Academy of Pediatrics recommends screening all children for autism at 18 months, emphasizing the need for effective therapies for toddlers at risk of developing ASD . This research is crucial as symptoms of Autism Spectrum Disorder (ASD) can emerge as early as 1.5 years, yet diagnoses often do not occur until around four years of age. Delayed diagnosis and intervention can adversely impact treatment outcomes, making early identification and

intervention vital for maximizing children's growth and development across all domains.

Our study focused on an experimental group of 35 very young children, with 31.4% aged between 2 to 2.6 years and 68.6% aged between 2.7 to 3 years. All participants were from nuclear families, with 77.1% being male. The majority (71%) followed Hinduism. Notably, a significant portion of parents (28.6%) had limited knowledge about autism spectrum disorder, and none were aware of early intervention programs (Table 1).

This demographic profile underscores the critical need for awareness and education regarding ASD and the benefits of early intervention. The lack of early intervention awareness among parents suggests a gap in public health education, which could delay critical developmental support for at-risk children. The high percentage of males in the study aligns with existing literature indicating a higher prevalence of ASD in males.

The study's intervention, which incorporated the AEPS®-3 system, aimed to address this gap by providing a comprehensive evaluation and intervention across six developmental domains. The significant improvements observed in the experimental group across all developmental domains, as compared to the control group, highlight the effectiveness of early and holistic intervention. These findings reinforce the necessity for implementing structured early screening and intervention programs. Early identification and intervention not only support better developmental outcomes but also reduce the long-term societal and

economic burdens associated with delayed ASD diagnosis and treatment. Future efforts should focus on increasing awareness and education about ASD among parents and caregivers, particularly in communities with limited access to information and resources. Additionally, larger-scale studies are recommended to further validate these findings and support the development of policy and intervention strategies at a broader level. The findings of this research reveal that early diagnosis and intervention significantly and positively impact children's growth and development across various domains. The experimental group demonstrated marked improvement, with overall development increasing by 66%. Specific domain improvements included fine motor skills (64%), gross motor abilities (65%), adaptive behavior (77%), cognitive behavior (52%), social communication (68%), and social behavior (78%) (see Figures 1-3). In contrast, the control group exhibited only a 51% increase in overall development over the study period.

Table I: Frequency and percentage of demographic variables for both experimental and control group Variables Experimental Group

Variables		Experimental Group (n=35)		Control Group (n=35)		Chi square test statistic (P value)
		Frequency (f)	Percentage (%)	Frequency (f)	Percentage (%)	
Age (in months)	24-30	11	31.4	10	28.6	0.068 (0.794)
	31-36	24	68.6	25	71.4	
Family type	Nuclear	35	100	35	100	-
	Joint	0	0	0	0	
Religion	Christian	6	17.1	4	11.4	1.24 (0.538)
	Hindu	25	71.4	24	68.6	
	Muslim	4	11.4	7	20.0	
Gender	Female	8	22.9	4	11.4	1.609 (0.205)
	Male	27	77.1	31	88.6	
Awareness	No	25	71.4	28	80.0	0.699

on ASD	Yes	10	28.6	7	20.0	(0.403)
Awareness on AEPS®-3	No	35	100	35	100	-
	Yes	0	0	0	0	

These results underscore the efficacy of early diagnosis and intervention in promoting children's development, particularly for families with children at risk of developing ASD. The substantial gains observed in the experimental group highlight the critical importance of incorporating comprehensive and early intervention programs. These programs not only address the multifaceted needs of children at risk for ASD but also foster improvements in physical, cognitive, and social domains.
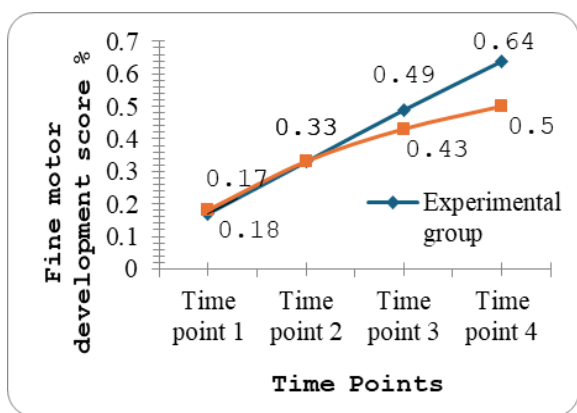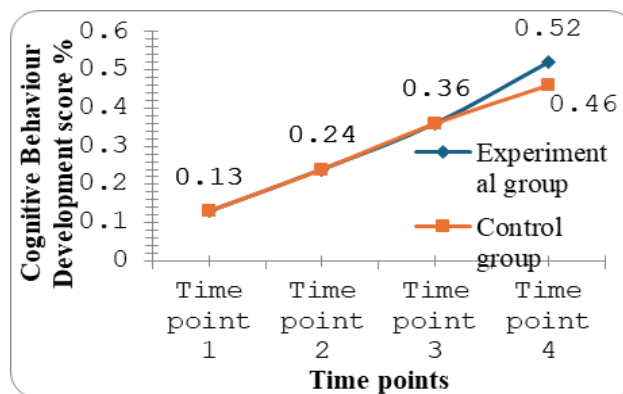

Figure 1: Profile plot showing change in Fine motor development score across time between groups
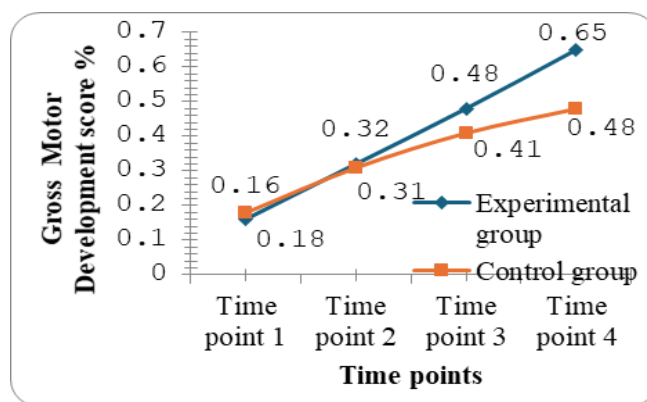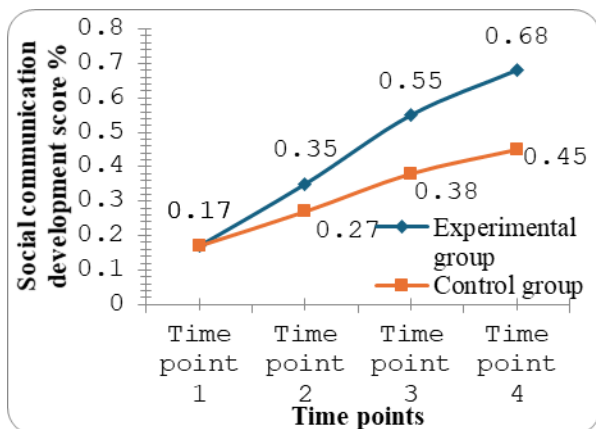

Figure 2: Profile plot showing change in Gross motor development score across time between groups
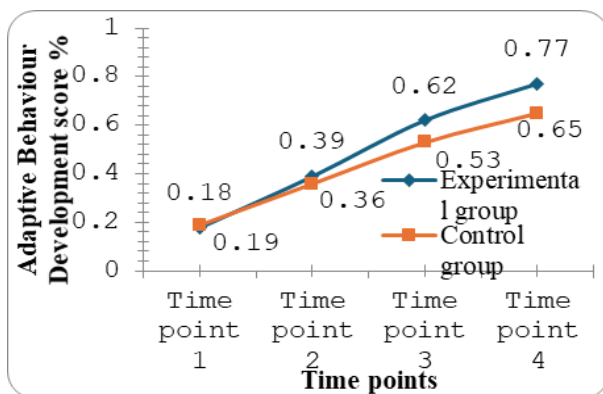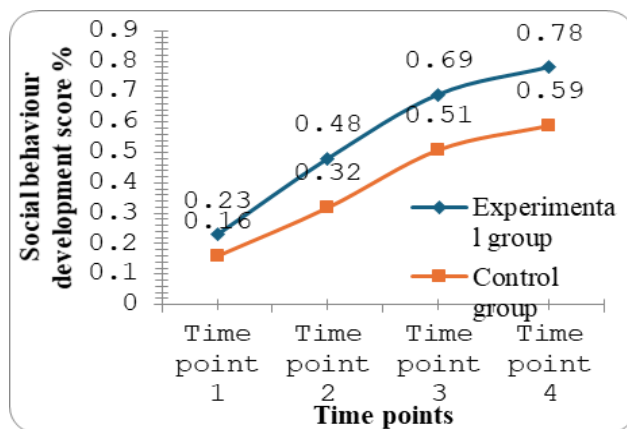

Figure 3: Profile plot showing change in Adaptive Behaviour Development score across time between groups
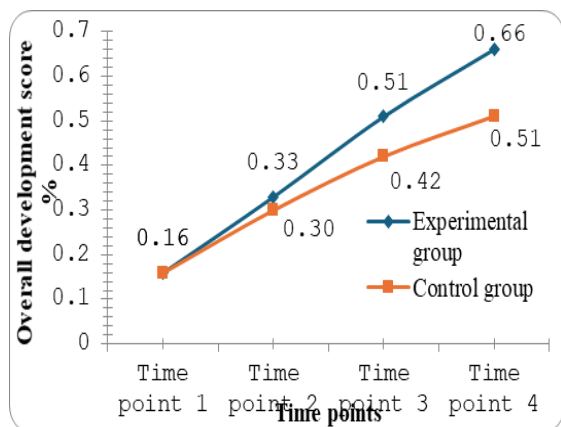

Figure 4: Profile plot showing change in Cognitive Behaviour Development score across time between groups

Figure 5: Profile plot showing change in Social communication development score across time between groups

Figure 6: Profile plot showing change in social behaviour development score across time between groups

Figure 7: Profile plot showing change in Overall

 development score across time between groups

Conclusion:

The research has substantial implications for families and the broader community. It demonstrates that early and comprehensive intervention strategies, involving both clinicians and parents, can lead to better developmental outcomes for children. This collaborative approach ensures that children receive consistent support across different environments, enhancing the effectiveness of the intervention. However, additional high-quality research is required to fully understand the impact of prodromal interventions, establish adaptive treatment pathways for low responders, personalize intervention approaches, sustain treatment effects, define the active ingredients of intervention approaches, determine the optimal timing for targeting specific skills, and maintain treatment effects over time. Future studies should focus on these areas to further refine and improve early intervention strategies for children with ASD. Furthermore, this study highlights the need for expanding expertise in this field, particularly in nursing practice, teaching, administration, and research. Enhancing knowledge and skills in these areas will ensure that practitioners can provide the best possible care and support for children with ASD and their families. In conclusion, this research provides compelling evidence that

early diagnosis and intervention are among the most effective strategies for enhancing children's development across multiple domains. Implementing systematic early screening and intervention programs can lead to markedly better developmental trajectories for children with ASD. These findings should inform policy and practice, emphasizing the importance of early and comprehensive intervention to maximize developmental outcomes and provide children with the best possible start in life. Future research should aim to replicate these findings in larger and more diverse populations, further validating the effectiveness of early intervention strategies and informing best practices in the field.

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