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Pediatrics

# EARLY DETECTION OF AUTISM SPECTRUM DISORDER AMONG 2-6 YEAR OLD CHILDREN BY COMMUNITY HEALTH WORKERS

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**ABSTRACT** Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder and early identification of ASD is a crucial aspect in early intervention. This study was done to assess the feasibility of screening ASD among 2-6 year old children by trained Anganwadi workers. All children between the ages of 2- 6 yrs residing in the ICDS Urban - I project area were screened for ASD using the tool Trivandrum Autism Behavior Checklist (TABC). A total of 7394 children were screened by Anganwadi workers and 48 children were found to be positive. All screen positives were further evaluated by a trained developmental therapist and 14 children were confirmed as having ASD. Prevalence of ASD in this study was 1.8 per 1000 children and the male female ratio of ASD was found to be 4:1, which was similar to the findings from other reports. Early identification of autism among children using simple screening tools like TABC by trained community health workers was found to be a feasible strategy.

**KEYWORDS :** Autism Spectrum Disorder, screening tools, community health workers, early identification

## Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impaired social interaction and communication, and by restricted and repetitive behaviours. Such behaviours include repetitive motor behaviours (hand flapping, body rocking), insistence on sameness, resistance to change and, in some cases, aggression or self-injury. It affects the functioning of the brain and hence multiple abilities can be affected. These impairments begin in early childhood and persist throughout life span.

There has been a rapid increase in the number of children diagnosed with autism, partly due to changes in diagnostic criteria and practices, inclusion of sub-threshold cases, age of children screened; but the question of whether actual prevalence has increased is unresolved. The prevalence of autism is about 1–2 per 1,000 people worldwide, and the Centre for Disease Control and Prevention (CDC) report that 14.6 per 1,000 children in the United States are diagnosed with ASD as of 2016(CDC Press Releases, 2016). Rehabilitation Council of India endorses a prevalence of ASD as 2 per 1000 population(Rehabilitation Council of India, 2010). A community based study conducted in India has reported a prevalence of 15 per 10000 children in the age group 1-10 years. This prevalence was significantly higher among children living in rural area when compared to urban(Raina et al., 2017).

Evidences suggest that mean age of diagnosis of ASD is 4-5 years in United States(Fountain, King, & Bearman, 2011). The risk factors for late diagnosis of ASD include parental education, socio economic status, race, sex, access to medical services and condition severity. Early diagnosis is the crucial first step to early intervention, widely seen as important for later behavioural and cognitive outcomes in autism(Rutter, 2006). Early intervention treatment services can greatly improve a child's development. It helps these children learn important skills like communication, social skills, functional skills, inclusion in regular classroom, child requiring fewer special education and other allied services in later life.

Little attention is paid on developmental disabilities at policy and implementation level in middle income countries like India where health programs focus mainly on child survival issues(Elsabbagh et al., 2012). Lack of effective early identification, referral facilities and intervention strategies for children with ASD is a huge barrier for significant development in core areas of impairments. Involving grass root level health workers can ease the early detection of developmental disorders. Simple and easily administrable screening tools can be used by community health workers along with adequate training for early detection of ASD. It is in this context; the present study was done to assess the feasibility of screening ASD among 2-6 year old children by trained Anganwadi workers in an urban ICDS block using the screening tool Trivandrum Autism Behaviour Checklist (Nair MKC, 2013).

## Methodology

This cross sectional study was done in Integrated Child Development Services (ICDS) project – Urban I which consisted of 7 wards in Thiruvananthapuram district, Kerala. These wards included Thiruvallam, Vizhinjam-1, Paruthikuzhy, Vizhinjam – II, Beemapally, Poonthura and Valiyathura. All children between the ages of 2- 6 yrs residing in the ICDS Urban - I project area were screened by trained Anganwadi workers (AWW).

Children were screened for ASD using Trivandrum Autism Behavior Checklist (TABC), which was developed and validated at Child Development Centre -CDC Kerala (Sensitivity: 80%, Specificity: 91.1%, Positive Predictive Value: 36.36% & Negative Predictive Value : 98.61%). The TABC screening test is divided into four components; social interaction, communication, behavioral characteristics and sensory integration. The scoring based on the responses of the four components are never (1), sometimes (2), often (3) and always (4). The severity of autism is graded on the basis of scoring: 20-35 > non autistic, 36-43 > mild to moderate autism, 44 and above is severe autism (Nair MKC, 2013).

The following steps were done for the study:

### *Step1: Training program for Anganwadi workers (AWW)*

AWW from ICDS Urban 1 block of Thiruvananthapuram district, were sensitized regarding the disabilities like autism and were given hands on training for the administration of TABC.

### *Step II: Screening of ASD by the AWW*

AWW conducted home visits and screened all the children in the age group of 2- 6yrs for autism using TABC. A total of 7394 children were screened. The completed forms were handed over to CDC Kerala for further evaluation.

### *Step III: Scrutinizing of completed data forms*

Completed forms were received from the CDPO (Child Development Project Officer) of ICDS Urban I project. Incomplete forms were discarded. All the forms received were checked by the team from CDC Kerala for the identification of screened positives.

### *Step IV: ASD confirmation camps*

A disability confirmation camp was conducted in the ICDS office premise, and all the children who were identified after screening were evaluated for autism by trained developmental therapists using Childhood Autism Rating Scale-CARS (Schopler, Reichler, DeVellis, & Daly, 1980). Those children identified and confirmed as having autism were referred to CDC Kerala and other centers for further management.

The data was further analyzed using SPSS Version 21.

**Results:**

A total of 7394 children were screened using TABC. Only 7382 forms were fully filled. Table 1 shows the characteristics of the children who were screened. About 38 percentage of the children belonged to the age group 2-3 years. More than one quarter of the children (29.3%) were in the age group 3-4 years. About 21 percent and 11percent of the children were in the age group 4-5 and 5-6 years respectively. More than 50 percent of the children in the study were male.

**Table 1: Profile of the children (n= 7382)**

| Characteristics | | Number (%) |
|---|---|---|
| **Age group** | 2-3yrs | 2814(38.1) |
| | 3-4yrs | 2160(29.3) |
| | 4-5yrs | 1573(21.3) |
| | 5-6yrs | 835(11.3) |
| **Gender** | Male | 3885(52.6) |
| | Female | 3497(47.4) |

Among the total 7382 children, 55 were found to be screen positive (table 2). Among them 27 children were identified in mild to moderate ASD category and 28 children in severe ASD category. The proportion of male children screened positive for ASD was more (1.1%) when compared to female children (0.4%).The ratio of male to female children screened positive for ASD using TABC was 4:1.

**Table 2: Classification autism based on TABC (n=7382)**

| TABC Score | Number (%) |
|---|---|
| Non autistic (up to 35) | 7327 (99.2) |
| Mild – moderate (36-43) | 27(0.4) |
| Severe (Above 43) | 28(0.4) |

**Table 3: Gender and prevalence of ASD using TABC**

| | | Prevalence of ASD (n = 7382) | |
|---|---|---|---|
| | | Autistic | Non Autistic |
| **Gender** | Male | 41(1.1%) | 3844(98.9%) |
| | Female | 14(0.4%) | 3483(99.6%) |
| | Total | 55(0.7%) | 7327(99.3%) |

All screen positives were asked to come for further evaluation at a medical camp. Forty eight children attended the evaluation camp. All of them were evaluated by a trained developmental therapist using CARS and 14 children were confirmed as having ASD. Table 4 shows the diagnosis of ASD among the screened positive children, using CARS. The male to female ratio of children confirmed as having ASD was 4:1.

**Table 4: Prevalence of ASD using CARS (n=48)**

| | Number (%) |
|---|---|
| **Autistic** (CARS score above 30) | 14 (21%) |
| **Non Autistic** | 34(71%) |
| **Autistic (n=14)** | |
| - Male | 11(79%) |
| - Female | 3(21%) |

**Discussion:**

Prevalence of ASD in this study is 1.8 per 1000 children, which is found to be similar to the findings reported by Rehabilitation Council of India which also endorse a prevalence of ASD as 2 per 1000 population(Rehabilitation Council of India, 2010). Also, the male to female ratio of children confirmed with ASD was 4:1 which is consistent with studies from elsewhere showing male predilection(Elsabbagh et al., 2012), (Rehabilitation Council of India, 2010), (Loomes, Hull, & Mandy, 2017). To our knowledge this study was the first to train community health workers to identify developmental disorders such as ASD.

At the community level children with ASD are identified lately due to the lack of parental knowledge, socioeconomic status and poor access to health care services(Rutter, 2006). This gap in early detection can be narrowed by community health workers.

Training and sensitizing grass root level health workers in early recognition of ASD and other similar developmental disorders can reduce the impairments and improve the quality of life of children.

**Conclusion:**

Early detection of children with ASD creates opportunities for the application of early intervention strategies to reduce or alleviate the severity of the problem and to make the child improved in the different aspects of development, thereby enabling her/him to adapt well with the society in a much better way. From this study it is clear that simple tool such as TABC can be effectively used by Anganwadi workers for early detection of ASD with appropriate training. This is a feasible community level strategy which can be further replicated for the early detection of children with ASD. Other community health workers like Junior Public Health nurses, Accredited social health activists can also be trained to undertake early detection process in the community.

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