Chapter 5

SUMMARY AND CONCLUSIONS

Autism, now termed as Autism Spectrum Disorder (ASD) as per DSM-5 classification, the commonly encountered disorder of children both in the community and clinical settings, is being diagnosed, assessed and evaluated by clinicians, psychologists and speech therapists for instituting appropriate treatment programs. Often the clinicians identify these children during the visit to their clinics for treatment of some other common ailments by the parents and sometimes this condition goes unnoticed due to non-reporting of the symptoms by parents. It has also been noticed that the parents often seek professional service of speech therapist for impairment in speech development without being aware of the primary condition of autism.

Usually the diagnosis of autism is arrived at by utilizing certain clinical criteria in which history of development and behavior of the child as reported by parents is very crucial. Besides, observing the behavioural pattern of the child, clinical examination will help in the clinical diagnosis of autism. Clinicians and Psychologists usually use DSM criteria for evaluation and the final diagnosis is arrived by positivity in neuro-developmental tests specific for diagnosis of autism.

Many of these tests are not freely available in India and if at all available, cultural differences of the items of the test are frequently encountered. The Childhood Autism Rating Scale (CARS) is the commonly used tool for identification of Autism, which was developed
and validated for children of western countries. The tool can be procured from the authorized suppliers in India and requires extensive training for the administration and interpretation. Hence, considering the requirement for a simple clinically useful measure for identification of autism, a new tool was developed. The following were the major observations of this study, titled “A study of Autism - Developing and Validating a Diagnostic Clinical Tool”.

Section-I

(i) The new clinical tool is named as “Childhood Autism Tool-Trivandrum (CAT-T)”. This clinical tool, for identification of autism in clinical settings can be used by Pediatricians, Psychiatrists, Psychologists and Speech therapists, among clinically doubtful cases presenting with impairment in social development, communication and abnormal behaviour among children of age between 2 and 6 years. The tool, which is available in Malayalam and English language, is simple and the 24 items of the tool have equal weightage and is designed in Likert Scale model with scoring. A cut-off score of 17 and above will categorize a child as having autism and a score below 17 as normal.

(ii) The CAT-T has 24 items to be rated on a Likert scale of 0 to 3 (no problems = 0; occasionally = 1; frequently = 2; always = 3) with equal weightage for all items and has been validated against CARS, the reference standard tool which is commonly used in our country.

(iii) CAT-T has good psychometric properties with sensitivity of 71% and specificity of 84% and positive predictive value of 92% and
hence can be used in clinics for identification of Autism among children of age between 2 and 6 years.

(iv) It also has acceptable test re-test reliability, inter-observer reliability and internal consistency, which shows that the tool has good stability and can be recommended in clinics for identification of Autism among children of age between 2 and 6 years.

(v) It has acceptable face validity, content validity, convergent validity and divergent validity. Exploratory factor analysis showed seven factor solution with 66.2% cumulative variance.

(vi) It will also help in the early detection of autism in clinical settings, which is essential for offering early intervention services for these children. It has also been proved that early intervention will help in ameliorating the symptoms of autism in the long run whereby the quality of life of these children will improve. Hence CAT-T may be used extensively in developmental clinics for identification of autism.

(vii) It is hoped that CAT-T, would give an impetus for the National programme the Rashtriya Bal Swasthya Karyakram (RBSK) for early detection of delays, deviations and disabilities including autism. RBSK programme of Government of India under National Health Mission is a new initiative for child health screening and early intervention services programme to improve overall quality of life of children through early detection of birth Defects, Diseases, Deficiencies, Developmental delays and Disability (4Ds).
Section-II

There is a general belief among clinicians, researchers and other stakeholders that the incidence of autism is increasing in our country, yet there are only a few studies done in India to identify the causative factors for the condition. Review of literature reveals that it is a disorder of multi-factorial origin with no proven aetiology. Genetic and environmental factors are postulated as reasons for the occurrence of the disease along with a large group of unknown factors where in with the available scientific knowledge, test and other gadgets, we cannot prove the aetiology. Hence a modest attempt was also made to find out some of the factors that have got an increased risk for autism.

It was observed that six factors were associated with a statistically significant increased risk of autism, viz., (i) male gender, (ii) higher socio-economic status, (iii) respiratory infection in mother, (iv) excessive foetal movement, (v) delayed cry and (vi) undesirable early child care practices.

(i) **Male gender:** It has been observed that autism is five times more common in male children than that in females. There is a pressing need for researchers to investigate the reasons for more prevalence of the condition in males compared to females.

(ii) **Higher socio economic status:** The data shows that socio-economic status has got a statistically significant risk for autism and reveal that more number of children from autism group belonged to upper and upper-middle socio-economic group.

(iii) **Antenatal and natal risk factors:** In this study respiratory infection in mother, excessive fetal movements and delayed cry have a significant association for the occurrence of autism. This
highlights the need for continuous follow-up and tracking the well-being of the fetus and offering appropriate medical management of pregnant mother during antenatal period. ‘Safe and risk approach method’ of delivery at appropriate designated hospitals is also warranted in order to reduce the incidence of perinatal and neonatal asphyxia (delayed cry).

(iv) **Undesirable early child care practices:** The environmental factors with special reference to child rearing practices could be analyzed and it was observed that a statistically high percentage of undesirable child rearing practices was present among families of children with autism with regard to the following factors; (i) mother not as primary care giver, (ii) not providing frequent outings to child, (iii) parents not visiting relatives with the child, (iv) relatives not visiting home, (v) child not playing with children of same age, (vi) parents not telling stories/singing songs to the child, (vii) family members not playing with child, (viii) child not attending day care center/nursery school, (ix) marital dissatisfaction among parents, (x) not breastfeeding the child up to 12 months. This highlights the need for providing child-friendly developmentally appropriate child rearing practices for fostering the development of the child.

Thus some of the contributory factors for autism during antenatal, natal and postnatal period of mother and environmental factors (child rearing practices) during infancy and early childhood have been identified in this study. These factors may be considered by the clinician during obstetric care of antenatal mothers as well as postnatal care. This
will help to minimize the rising prevalence of autism in our country, as primary prevention is the hallmark of prevention of disability.

Now that CAT-T is available free of cost for identification of autism among children from the age of 2 years, this simple, easy to administer tool may be used by pediatricians, clinical psychologists and speech therapists in their clinical practice. Early detection of autism will no longer be a difficult task with CAT-T support. It will definitely assist the early intervention program for improving the neuro-developmental status of the child. It is also presumed that this will go a long way in reducing the incidence of the disorder, positively reducing the burden of disability thus improving the quality of life of the affected children and their parents, thereby giving its dividends for the welfare of our nation.