



AUTISTIC CHILDREN IN INDIA: AN OVERVIEW OR INSIGHT

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Abstract

Autism is a mental disorder which severely affects the socio-cultural behaviour of the child and it was taken in the range of diagnosis very late as earlier it was categorized as schizophrenia. The concept of autism was coined in 1911 by the German psychiatrist Eugen Bleuler to describe a symptom of the most severe cases of schizophrenia, a concept he had also created. According to Bleuler, autistic thinking was characterized by infantile wishes to avoid unsatisfying realities and replace them with fantasies and hallucinations. ‘Autism’ defined the subject’s symbolic ‘inner life’ and was not readily accessible to observers (Bleuler, 1950). Leo Kammer during was the first person to find this disorder in 1940s and gave it the name autism. Thereafter motley of psychologists and researchers started working on autistic children and thus brought to the fore many aspects of it. The present study aims at understanding of autism with its background in Indian context. The researcher has concluded that the minimum age for diagnosis of autism is forty-four months. Owing to the cultural traditions autism is often ignored in India and the children with this disorder are kept with the normal one; and ironically India has the largest cases of autism. The child with autistic disorder is regarded as the result of destiny and fate here. There is lack of social awareness about autism in India. In present study attempts have been made to find out the perceptions, abnormality and behaviour of the children with autism in India; how they are different from the rest of the children.

Key words: autism, disorder, culture, society, children, diagnosis

INTRODUCTION

Autistic is a complex neurodevelopment disorder defined by the presence of social deficits, abnormalities in communication, presence of stereotyped, repetitive behavior and a characteristics course. The national trust for the welfare of person with autism, cerebral palsy , mental retardation and multiple disabilities Act 1999 defined “Autism as a condition of uneven skill development primarily affecting the communication and social abilities of a person marked by repetitive and ritualistic behaviour. Earlier, individuals with severe and moderate autism were categorized as “Mentally retarded and schizophrenia.” India is a populous country of nearly 1.3 billion people with children less than 15 years constituting nearly one third of the population. It has been estimated that more than 2 million people might be affected with autism in India. Most of the reported studies on autism are based upon hospital based data and thus lack information on the prevalence estimates of this disorder in India. There are only a few studies focusing on its prevalence in the community settings. Furthermore, lack of uniform application of fully validated and translated autism



diagnostic tools makes it difficult to estimate the exact prevalence of autism. There is also underrecognition of the disorder due to a delay in the diagnosis of autism at a young age.

Leo Kammer during 1940s was the first person to identify and differentiated these children and named them as “Autistic” and proposed that the problems in the children with autism are due to difficulties in the parent-child relationship (Hawlin1998). It is heartening to note that during the same period, a viennese pediatrician A. Ronald while working in the Darjeeling, India described some abnormal/difficult children with similar characteristics. Then on ward many researches (Rimland, 1964; Rutenberg, 1971; Rutter, 1974 and so on) started working on various aspects of autism. Until the mid 1980s, autism was wrongly viewed as a psychiatric disorder (Aieardi 1998). Since late 1980, autism has been rightly recognized to be a neurodevelopment disorders due to underlying disorder of a brain development (Karande 2006). While the disorder is not rare, a multitude of people with autism in India have not been diagnosed and -- more critically -- do not receive the services they need. This problem occurs in many countries, but is especially true in India where there is a tremendous lack of awareness and misunderstanding about autism among the medical professionals, who may either misdiagnose or under diagnose the condition. Obtaining an accurate diagnosis is one of the major difficulties faced by parents of children with autism in India. A parent may take their child to a pediatrician only to be reassured that their child is just "slow." Unsatisfied, they may visit a psychologist, to be told their child is "mentally subnormal." Convinced that their child does not fit the typical picture of mental retardation, they may visit a psychiatrist, to be told that their child has attention deficit disorder, and must be put on medication to control hyperactivity. After months of sedation and unsatisfactory progress, they may again begin a cycle of searching for the correct name for their child’s problem.

Fortunately, the process of obtaining a diagnosis of autism in India is improving in the major cities, as more pediatricians become aware of the condition. Some doctors may feel that nothing can be gained by a diagnosis of autism if the services are not available; yet, as more children are diagnosed as autistic and more awareness of the disorder spreads, there will be a demand for services. Schools will be forced to educate themselves if they find that more of the population they serve is autistic. Admittedly, there are not enough services to meet the needs of mentally retarded children and adults in India, let alone those who are autistic. Let this then be an impetus to create more services, and ensure that the special needs of autistic children are not ignored. There is also an urgent need to begin planning residences and centers for these children for when they become adults: people with autism have a normal life span and many will require considerable support after their parents’ death. Currently, the needs of autistic children in India are not being met in either the regular or special education systems. With an understanding teacher or possibly an aide, a more able autistic child can function very well in a regular school, and learn valuable social skills from his peers. However, even children with very high I.Q.’s are often not permitted in regular classes. Additionally, the rigidity and pressure of schools in India can make it difficult for



an autistic child to cope without special allowances. Some children with higher support needs, who form the majority of autistic children, may attend special schools, but these schools often lack an understanding of effective methods of handling the challenging behaviours of autistic children. As one psychologist noted, "The kids just get 'dumped' or ignored at the special schools." Children with autism are frequently refused admission in these special schools because officials protest they are not equipped to handle autistic children, who are sometimes more challenging than children with mental retardation alone. We firmly believe that special schools need to invest in learning these techniques so that they can provide the necessary help to both the children and the families.

What is Autism?

A lack of ability relative to personal or group standard or norm is known as disability. It may involve physical impairment, sensory impairment, cognitive or intellectual impairment mental disorder (also known as psychiatric or psychosocial disabilities or various types of chronic disorders. A disability may occur during a person's lifetime or may present from birth. Mental disorder or mental illness is a psychological or behavioural pattern that occurs in an individual and is thought distress or disability that is not expected as part of normal development or culture. Autism is a mental disease or disorder characterized by difficulties and problems in talking, interacting, communicating and performing activities. Autism is characterized in many different degrees, one worse than the other. The disorder is commonly established in the first 2 years of age; anyhow, they are autistic since the first day they were born. According to scientists, autism is much more likely in boys than in girls: one in 88 girls and 1 in 54 boys. Autism is a serious developmental disorder that affects a child's ability to communicate and interact with others. For reasons that are not clear, the disease is three to four times more common in boys than it is in girls. Children with autism often are self-absorbed and seem to exist in a private world where they are unable to successfully communicate and interact with others. They may have difficulties in developing language skills and understanding what others say to them. Autism is known as a complex developmental disability. Experts believe that Autism presents itself during the first three years of a person's life. The condition is the result of a neurological disorder that has an effect on normal brain function, affecting development of the person's communication and social interaction skills. People with autism have issues with non-verbal communication, a wide range of social interactions. Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills, and rigid, repetitive behaviors" (WebMD, 2012a). In another words, autism is a lifelong disability that blocks the learning, language communication, emotional and social development of a child. Another way to define autism is that it is a developmental disorder that appears during the first 3 years of life, and affects the brain's normal functions.



Review

Charles Darwin acknowledges that facts are of no use unless they support a point of view. On the other hand, points of view are of little value unless they are supported by facts. The intent of the literature review is to provide background knowledge on the relevant aspects of autism. The intent of the present study/paper is to provide a better understanding of autism in Indian perspective.

Children who receive early intervention tend to have better communication skills and fewer out-of-control behaviors, and parents of these children often have a greater understanding and acceptance of their child's disorder (Caramagno 1992). However, in a survey of parents of 128 children with autism (Vostainis et al 1994) it was found that, although parents had suspected that something was wrong with their child's development at an average age of 17 months, the average age for the diagnosis of autism at the first referral was 44 months. The checklist for autism in toddlers chart (Baron-cohen, Allen and Gillberg, 1992) and observation by the clinicians (5 items). The features at 18 months, which predict the diagnosis of autism include the absence of five aspects of functioning: i.e. pretend play, social interest, social play, protodeclarative pointing and joint attention (Baired, et al 2000)

Indian Context

Of all the countries in which autism has been described, India has by far the largest literature on the disorder. Phatarphekar (2003) estimated the muted truth is that about 2 million people could have autism in India. There is an urgent need to plan a large, prospective, community-based investigation to fill the gaps in the knowledge about autism in India. A study by Nair et al., (Centers for Disease Control and Prevention (CDC), Kerala 16) demonstrated the highest sample size with screening of 101,438 children. This study was conducted in Kerala and was aimed at diagnosing most of the developmental disabilities such as developmental delay, global developmental delay, autism, and cerebral palsy using simple and standardized screening tools. There is a need for such large population-based epidemiological surveys, which will be helpful in estimating the exact burden of autism in our country. Chari (2004) shared her experience based on her clinical work to help the parents and the trainers of children with autism. Karkar(1978) points out, in India the child is considered to be a gift of God, and is nurtured with indulgence. The traditional Indian child-rearing and social relationships allow the child to mature at his own pace. Hence there is no deliberate effort to make him autonomous. This would delay the process of early detection even further. The Indian belief in the doctrine of karma and especially the psychological notions associated with it, perhaps make it easier for the family to accept an individual with autism among them. Like every other person, the child with autism is believed to be born with a destiny or fate of his own.

Due to limited awareness and sensitization in India, there is a lot of limitation in the correct diagnosis of autism. The diagnosis is further complicated by the uneven development profile of a child with autism. Researcher findings indicate that nearly all the children with severe autism also may be mentally challenged. In the case of mental retardation there is



global impairment and children have an overall delay in development that follows normal stages. On the other hand, autism is characterized by an uneven skill profile and often severe sensory defensiveness, which can result in unusual behaviours, even in the presence of mental retardation.

The present paper aimed at gaining an insight on children with autism in India. The focus was to study the, the conditions, perception of the people around the child, the opportunities the child gets for its education and the skill and ability level of the child. Motivation of the present study comes from the observation of typical physical and psychological behavior of these children, special talents and the lack of sufficient research in India.

Conclusion and suggestions

All the children with special needs must have the right to education, employment, social security and health benefits among other special aids like their non-autistic counterparts. The rights of autistic child in India provide him/her with the best valuation of the disorder through a team of doctors, psychologists, and trained therapists or service providers. The government of India offers several legal rights and protections to citizens with autism spectrum disorder. They ensure that all are treated justly and have access to all services entitled by others. For the right to free and appropriate education, the law places the child in an appropriate educational setting, where they are integrated into different schools according to the severity of the symptoms. Those with mild or moderate disabilities may be integrated into normal schools, whereas children with severe autism spectrum disorder are enrolled in special schools. For children with learning disabilities, remedial classes and vocational courses are provided by special schools. Our perception of autism has evolved over time. Sixty years ago autism was nothing more than an unrecognized developmental delay generally lumped in with mental retardation. Today it is recognized as an independent neurologically based disorder of significance, a major public health problem, and a topic of much research. Researchers have struggled to find a cause for the disorder without great success. Despite this difficulty, research continues in ever more sophisticated directions. Numerous treatments have been developed that help children with autism and PDD to maximize their potential to learn and become socially fluent, no matter how impaired they may be. Though no breakthroughs appear likely to occur any time soon, there is cause for hope. There is no real consensus among the medical fraternity regarding autism statistics. This discord is a result of the differential diagnosis methods employed for the detection of autism. Some experts believe that environmental factors like mercury poisoning, dietary habits and vaccine sensitivity can cause autism. Government needs to do more to tackle the problem of childhood autism – an analysis of the budget allocation towards autism research in the last twenty years. Treatment alone cannot provide relief to students with autism. Complete support of family, teachers and classmates can help a great deal. Because autism in children leads to family distress, treatment program should cover the family of the autism affected children. In India lot of work required on autism by govt. like to open NGO and special educational institutes where they learn how to teach autism children. The



Constitution of India provides equal rights to every legal citizen. This also applies to people irrespective of their caste and disabilities (physical or mental). There is no cure for the disease. However, it can be managed with the help of medications and specialist education. Early intervention services can help in child's improvement. These services include that help child talk, walk and interact with others. Therefore, it is important to talk to child's doctor as soon as possible. As India is a vast country, there is an urgent need to have large population based surveys with united screening and diagnostic tools. Autism in India also needs to be viewed in the context of attitudes toward disability more generally. Traditionally there has been stigma attached to disability— shame, embarrassment, concerns about inadequate parenting— perceptions that are shared by many countries worldwide. Autism comes with unusual behaviors, fuelling beliefs about what affected the children. Since autistic children were not seen, they did not exist, which acted as a barrier to awareness. It isolated families, creating a cycle of ignorance and superstition. In recent years the stigma has lessened and there is greater acceptance. The autism movement in India has come a long way in the past two decades; identification and diagnoses are made at earlier ages, there are more services that cater to the needs of individuals with autism, there are also some changes in the awareness levels in the general population. But there is still a lot of work to be done. If people with autism are to have an opportunity to reach their maximum potential and have dignified futures, the community of parents, siblings, other relatives, and professionals will have to continue to work together as a team and advocate for the rights of this often marginalized and vulnerable sector.

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