

## **Pervasive Developmental Disorders: Indian Scene**

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### **Introduction**

Pervasive developmental disorders (PDDs) are characterized by slow, limited and atypical developmental processes with onset in the early years of life. The condition leads on to disabilities in virtually all the psychological and behavioral sectors with prominent disturbances in social, communicative and cognitive spheres. PDDs include the prototypic Childhood autism, Rett's syndrome, Childhood Disintegrative Disorder (CDD), Asperger's syndrome and Atypical autism. Except for one additional category (hyper kinetic stereotyped movement disorder in ICD-10), the disorders included in ICD 10 (World Health Organization, 1992) and DSM IV (American Psychiatric Association, 1994) are identical.

### **History**

Autism was first described by Leo Kanner in 1943 in his classic report of 11 children with "autistic disturbances of affective contact" (Kanner, 1943).

A Viennese paediatrician A. Ronald while working in Darjeeling, India, in 1940's came across some abnormal/difficult children. The description given by Ronald bears similarity to Kanner's observation. Ronald also made a note of the fact that the problems of such children extended to the whole of their mental personality. Thus it is heartening to note that one of the earliest descriptions of autism came all the way from India.

### **Diagnosis**

Diagnosis of PDD is largely clinical. DSM IV and ICD -10 have defined autism almost similarly. India follows ICD -10 diagnostic criteria. The criteria for the diagnosis of PDD are strict and they help in the diagnosis of mainly severe cases. Since cases of autism spectrum disorders may visit any doctor, most commonly pediatricians, who are not very familiar with the diagnostic criteria of ICD or DSM, it is possible that milder cases of PDD are missed. However, it was observed that 937 professionals, belonging to three different categories, pediatricians, psychiatrists and psychologists; generally agreed about necessary characteristics needed for diagnosis of autism (Daley, 2002). In another survey by Action for Autism, about one-third of 677 pediatricians endorsed the outdated

view of autism being more common in higher socio-economic families and occurring a result of cold rejecting parents. 60% of them believed that emotional factors played a major role in the etiology and half agreed that autistic children would “outgrow” the autism ([www.autismindia.org](http://www.autismindia.org)). These observations highlight the need for training health professionals who are involved in care of persons afflicted with autism.

## **Research**

### *a) Epidemiology:*

Several researchers have claimed that autism is either rare or nonexistent or if present is not reported in places such as India (Lotter, 1980; Sanua, 1984). This notion probably stems from the fact that there hasn't been even a single attempt to find out prevalence rates of PDD in general population in the Indian subcontinent. A handful of general population studies which have calculated childhood psychiatric morbidity haven't reported the data for autism spectrum disorders. There are, however, a few clinic based prevalence studies, case series and case reports which show that health professionals do see cases of PDD. It is possible that early literature reporting prevalence of childhood schizophrenia, psychoses and mental retardation included misdiagnosed cases of autism. As the diagnostic criteria for PDD became more refined the number of studies reporting autism cases increased.

The earliest report of clinic prevalence of infantile autism was by Hoch, a trained psychoanalyst, in 1967. In an Indian Council of Medical Research funded study done at a private missionary hospital she found 2.9% cases were of infantile autism. No diagnostic criteria were used. All the cases were diagnosed clinically (Hoch, 1967). One must note that autism at that time was explained and understood more in psychological/psychodynamic terms than biological. Subsequently, a series of seven cases were reported from a mental retardation clinic at NIMHANS, Bangalore. The sex ratio of the cases was 1.33:1 and they had an age range of 3 to 12 years (Narayanan, 1978).

In a retrospective chart review between 1980 and 1982, Malhotra & Chaturvedi (1984) found only 4 cases, which met ICD-9 criteria for childhood psychotic disorders. The authors included infantile autism cases under this category. The clinical or socio-demographic characteristics of the cases were not mentioned.

Srinath and coworkers (Srinath et al, 1989) from NIMHANS, Bangalore did a retrospective review of cases registered from 1981 to 1984 in the child psychiatry clinic. A total of 31 cases met the ICD-9 criteria for autism. Out of these cases only 17 fulfilled the criteria laid down by DSM III, which probably reflects the difference in approach to the diagnosis between two classificatory systems. The cases ranged from 2.5 to 14 years of age. Males constituted the bulk (M: F = 7.5: 1), which is higher than that reported internationally. Most were from well to do families. None had faced or were facing adverse psychosocial situations. All developed symptoms by 30 months. Two patients had co-morbid seizure disorder (Srinath et al, 1989).

There have also been attempts by Indian researchers to look for autistic features and autism in children with mental retardation. This is not surprising as it is well known that mental retardation is co-morbid with autism in up to 70% of cases. International studies have found rates ranging between 0.6% (Lotter, 1978) and 12.8% (Wing & Gould, 1979). Kar et al (1993) in a study from north eastern part of India found co-morbid autistic disorder in 13% of 55 mentally retarded children. Purkayastha et al (1997) found co-morbid autism in 4.7% of 874 patients of mental retardation. In another study (Kar et al, 1997) done at child psychiatry clinic of Central Institute of Psychiatry, Ranchi, 96% cases of mentally retarded children had some autistic features. Bharath et al (1997) from National Institute of Mental Health and Neurosciences, Bangalore, reviewed inpatients' admissions over a 1 year period in the child psychiatry unit. Using ICD-9 criteria 6 cases out of a total of 143 met the criteria for autism. Reason for in patient admission was observation, diagnostic clarification, counselling of parents and initiation of treatment.

All the above studies have been from psychiatric units of a general or psychiatric hospitals. Singhi and Malhi (2001) attempted for the first time in India to identify cases of autism in a paediatric clinic. They reviewed case notes of all the cases registered at the paediatric neurology clinic of Post Graduate Institute of Medical Education and Research, Chandigarh, over a 2 years period. They found 16 children <5 years of age meeting the DSM IV criteria for autism. The cases were referred to them for speech (n=10) and /or developmental delay (n=6). Cases were in a sex ratio of 1.3:1 which is less than that reported elsewhere. Authors had included only those children who were less than 5 years of age, which limits the generalizability of the socio clinical data of their cases. Childhood Autism Rating Scale's score was in severely autistic range in 62.5% of cases. About 25% of cases had normal development up to at least 18 months of age and after that there was regression in the areas of language and behaviour. It is possible that other PDDs like Rett's syndrome and Childhood disintegrative disorder may have been misdiagnosed as autism (Singhi & Malhi, 2001).

In addition to these reports there are a few case reports and case series which have described cases of autism. Apart from psychiatrists, psychologists and paediatricians; speech therapists have also reported on cases referred to them for speech therapy in two publications (Kapur, 1989; Gore, 1989).

Apart from typical autism, there are a few published reports on other PDDs, mainly CDDs. Malhotra and Singh from PGIMER, Chandigarh published socio clinical and investigation findings of 5 cases of CDDs registered at child and adolescent psychiatry clinic from 1980 to 1989. These cases constituted 0.22% of the total cases (2259) registered during this period. Age at first contact ranged between 5.5 to 12 years. Regression started at 7.4 years in one, while in all the other cases it started between 3 and 4.5 years of age. Unusually rapid onset (1 to 4 weeks) was a notable finding of this study. EEG showed seizure activity in one while nonspecific rhythm abnormalities were found in two cases. CT scan head was normal in all the cases (Malhotra & Singh, 1993). Jaydeokar (1997) published his observations of a case of CDD in a case report.

Malhotra and Gupta from PGIMER, Chandigarh in a retrospective review of cases registered at child and adolescent psychiatry clinic between 1989 and 1999 found 12 cases of CDD, which is about 0.45% of all the cases. Average age at onset was 3.76 years and average age of presentation to the clinic was 7.46 years. Sex ratio of 5:1 is consistent with other reports. Again a rapid onset of illness was noted which is unusual, as a gradual onset is much more widely seen and reported internationally (Malhotra & Gupta, 2002).

As regard to other PDDs there is only one case series of three cases of Asperger's syndrome by Malhotra et al from PGIMER. The cases had been registered from 1989 to 1999 and they fulfilled ICD-10 diagnostic criteria. All the cases were males who exhibited classical symptoms in the form of qualitative abnormalities in social interaction and reciprocity. ADHD was co-morbid in two and MR in one case.

Malhotra et al (2002) reported two cases of Rett's syndrome in the period between 1989 and 1999 at the CAP (Child and Adolescent Psychiatry Clinic), PGIMER, Chandigarh. Both were females with a period of normal development up to 12 and 18 months respectively. Both the cases showed classical symptoms.

In a recently published study Malhotra et al (2003) compared the socio-demographic and clinical profile of PDD patients registered at CAP Clinic, PGIMER, and Chandigarh between 1989 and 1999. Out of 2942 cases 46 cases (1.6%) met ICD-10 criteria for different PDDs. 22 cases were of typical autism, 12 cases each were of CDDs and other PDDs. 5 cases met criteria for atypical autism, 4 were of Asperger's syndrome and the rest were of Rett's syndrome (n=2) and PDD unspecified (n=1). Relatively high proportion (26%) of cases of CDD is notable as it has been suggested that CDD is only about one-tenth as common as autism. Seventy eight percent of the total sample was male, all exhibited classical symptoms, and temperamental variations were noted in the areas of activity, rhythmicity and attention span in most of the cases. Comparisons between the three groups of typical autism (n=22), CDD (n=12) and other PDDs (n=12) on various sociodemographic and clinical parameters showed significant differences on various socio clinical parameters like socioeconomic status, onset of illness, age at onset, temperamental variables, neurotic traits, delay in milestones and intelligence quotient (Malhotra et al, 2003). These findings lend credence to subtyping of PDDs as advocated by current classificatory systems.

Based upon above findings one can safely conclude that autism spectrum disorders do exist in the Indian subcontinent. If one chooses to ignore rapid onset of illness in CDDs as reported in India, the clinical picture is identical to that reported internationally. Generalizability of the results of Indian studies is however limited, as all the studies are clinic based, retrospective and on small sample sizes. There is an urgent need to plan a large, prospective, community based investigation to fill up the gaps in the knowledge about autism in India.

***b) Neurobiology:***

Research into neurobiology of developmental disorders is still in a nascent stage in India. Few attempts have been made, but the enthusiasm of some of the older generation researchers has not rubbed on to their younger colleagues, because after a few promising attempts in 1980s, no reports have been published.

Shivashankar and Satishchandra from NIMHANS studied Auditory Brainstem Responses (ABR) of seven autistic children and compared them with the responses in twenty normal children. The study revealed pathological ABR in three subjects (42.8%) pointing towards dysfunction at brainstem level. Pathological ABR also argues for the faulty modulation of the auditory input thus leading to failure in the development of complex cognitive skills. The results also showed that there existed two groups of autistic children, one with normal and other with abnormal ABRs (Shivashankar & Satishchandra, 1989). The results obtained were similar to other reports.

Manjunatha et al (1989) did a crypto genetic investigation in autistic children with the aims of finding the association and prevalence of fragile X syndrome in autistic children. Though none of the six cases studied had fragile X chromosome, fragile sites were noted in autosomes 1, 2, 3, 5 and 6. However, significance of this finding is limited as these sites are also observed in general population and mentally retarded subjects (Manjunatha et al, 1989; Fryns et al, 1984).

### ***c) Autism in Cultural Context:***

Though the quality and quantity of research which has been carried out in India is not very good; it is still the best among all the developing countries.

There are certain socio cultural characteristics which are very different from the place where understanding of autism has taken its shape i.e. the western world. Indians largely emphasize conformity to social norms and value social relatedness. This is important in context of the diagnosis/ identification of a disorder which has prominent deficiencies in social interaction and reciprocity. Parents might recognize social symptoms earlier. The family of a person unable to perform these roles may be more affected by the disorder than a family which pays less importance to social relatedness. This issue was examined by T. Delay in a yet unpublished study. She examined the process of parental recognition and found that Indian parents noticed something different about their child between 6-10 months later than that has been found for parents in the USA. It is not possible to determine from this study whether symptoms in Indian children appeared later than children in West, but it is important to note that majority of families noticed social difficulties first. This was expected as Indian mothers and their young children have “protracted intimacy” and they are more indulgent and protective. Parents may thus be more sensitive to the unusual aloofness of their child and might recognize social symptoms earlier (Kalkar, 1981).

## **Needs**

### ***a) Parents and Patients:***

Children with autism have certain special needs. The first and foremost is recognition. Such children must be diagnosed carefully and not labelled as mentally retarded. There is an urgent need to establish specialized centers for identification of such children. Majority of such children are not diagnosed due to lack of awareness among general public and to some extent even among the health professionals. Parents, who need help, do not know where to go. They keep shuttling between general physicians, paediatricians, psychologists and psychiatrists before getting the proper diagnosis and treatment. The cases which get the proper diagnosis and treatment are actually only a very small proportion of the total number of cases prevalent in the community. There is also a lack of will and enthusiasm among health professionals to treat such children as it requires utmost dedication, time and devotion to manage such children. Many find the entire exercise unrewarding. The problem is furthered by the fact that there are a very few trained professionals capable of carrying out meaningful intervention with autistic children.

There is also a need to explore the effective ways of integrating autistic children into the main-stream education.

Attention also needs to be paid to the needs of parents. They need to be educated and supported throughout the process of diagnosis and need to be made active collaborators in treatment planning. Support in the form of reassurance, listening to their problems patiently, and encouragement etc. is needed at every stage in the process of diagnosis and treatment.

#### ***b) Treatment and Care Services:***

Treatment and care to PDD patients is provided by both health and non-governmental social organizations. After getting the diagnostic label, parents either stick to the health agencies for the treatment and care or move towards social organizations.

In India, psychiatrists, psychologists, speech therapists and paediatricians have been providing treatment and care to such children and their parents. However, there have been no sincere efforts by the government to establish centers which would provide specialist care. Most of the cases are seen and managed at overcrowded government general hospitals or psychiatric hospitals. Lack of trained personnel is also a serious handicap. Few private centers which provide specialist care are out of reach of common people. Some significant gains have been made in last few years by the non-governmental social organizations. They have formed national autism societies, parents associations and support groups. Action for Autism (AFA), Academy for Severe Handicaps and Autism (ASHA) are important ones. They have worked towards promoting greater awareness among professionals. They have called for a legislation to protect and support children with autism. They have conducted workshops, teacher training courses and live demonstration of methods to handle children, and have promoted parent empowerment through parents groups. AFA practices "open door teaching method" in which the techniques used around the world are tested and modified to the needs of Indian children.

It also conducts “Mother-Child Interaction Programme”, a home based programme aimed at training parents.

***c) Interventions:***

A multimodal treatment plan has been advocated and both the child and the caregivers need to participate in the treatment. The treatment heavily relies on non-pharmacological measures. Pharmacological measures are mostly reserved for managing disruptive behaviours, sleep problems, self injurious behaviours etc. The interventions have to be tailored to the needs of the child and the parents.

Not much literature is available in India on treatment of autistic children. Earliest report was from NIMHANS by H.S. Narayanan in 1978 who published his experience with the management of seven autistic children. All were treated using behaviour therapy, and speech therapy<sup>9</sup>. Other published data on treatment of such children has mostly been in the form of case reports and series wherein brief description of the treatment modalities used has been given. Antipsychotics like haloperidol (0.5-5 mg/d) and thioridazine have been used. There also have been reports of using amphetamines, buspirone for associated hyperactivity.

There are two detailed reports of treatment/ interventions carried out with autistic children; both have involved parents in their treatment protocols. Naik et al from Hyderabad use Behaviour modification and educational package from the TEACCH protocol (the Treatment and Education of Autistic and related Communication Handicapped Children). The treatment includes sensory integration, parent counselling and training, speech therapy, and picture exchange communication systems, which helps the child learn how to ask questions, make comments and express desires.

Malhotra et al (2002) from PGIMER, Chandigarh published their experience with psychological intervention with parents of autistic children. Treatment methods were drawn from TEACCH protocol. Emphasis was given on behavioural strategies aimed at enhancing eye to eye contact, reduction of maladaptive behaviour, structuring time, activities and physical environment. Considerable time was given to parents to teach them these techniques, to educate them about the nature of the disorder and its management, and a supportive mode of counselling to help them deal with emotional fall out of the diagnosis. These were used on 5 children with autism in 3-6 sessions of 45-60 minutes each. Results showed that the parents found this brief contact helpful. They found emotional aspects of the support to be the most helpful.

There are also reports of some alternative therapies for treating children with autism. G-therapy, which involves intake of a special combination of herbal extracts in potentiated form and salts of body, has been reported to be beneficial for treatment of a variety of neurodevelopmental disabilities including autism. Dr. G. Oswal reported beneficial effects of G-therapy in 168 patients of autistic spectrum disorder. Improvement was reported in speech, cognitive abilities, social interaction, behaviour and hyperactivity. There are many reports from various part of world, mainly western, regarding beneficial

effects of vitamin B6, magnesium supplements, dimethylglycine. It may be possible that G therapy includes some of these components ([www.G-therapy.org](http://www.G-therapy.org)).

**d) Laws:**

After relentless efforts of non-governmental organizations and parents associations autism was legally recognized by the government of India in 1999 as a disorder. Till then children with such a diagnosis were ineligible for the disability benefits, and schools specially designed for autistic children were denied any funding from the state. Legal recognition has enabled such children to derive the benefits under Persons with Disability Act, ie. equal opportunity, protection of rights, and prevention of discrimination (Persons with Disabilities Act, 1995).

The National Trust under Ministry of Social Justice and Empowerment, Government of India, set up under the “National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities” (Act 44 of 1999) works towards following goals:

- to enable and empower persons with disability to live independently into their community;
- to strengthen facilities, provide support to disabled;
- to support registered organizations to provide need based services to families of disabled;
- to deal with problems of disabled without family support;
- to promote measures for care and protection of disabled when caregivers die; and
- to facilitate realization of equal opportunities, protection of rights and full participation.

The Trust also publishes parent education booklets in 13 regional languages and sells it at a nominal cost (National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 44 of 1999).

**Conclusions**

One can take home certain messages after this detailed evaluation of autism scene in India.

1. Autism spectrum disorders are not uncommon in India.
2. They present clinically in a manner similar to that reported internationally.
3. Awareness among professionals and public is increasing and this has had an effect on the government as well.
4. Certain critical issues which are pertinent for India remain.

What after getting the diagnostic label? Receiving a diagnosis of autism in India does not usually result in any different course of intervention or education than did a more general diagnosis of mental retardation. Very few trained personnel are available to manage such patients. There is also a sense of frustration among professionals who feel

unrewarded after the diagnostic exercise. Some times diagnosis of autism backfires on the child and he/she is denied admissions to school. Last, but not the least, what is to be done after the parents die?

1. A more concerted effort is required from professionals, general public, parents and the government to address many of these issues.

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