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From symptom recognition to diagnosis: children with autism in urban India

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Abstract

The period of time between initial recognition of a symptom and initial diagnosis warrants examination because it can serve as a window into broader cultural factors and allow for more immediate treatment. Research on this process among parents of autistic children to date has been useful, but has been limited to families in Western countries, whereas autism occurs all over the world. The current study provides data on the process of initial symptom recognition, help-seeking, and initial diagnosis of a pervasive developmental disorder among 95 families of autistic children in India. The findings suggest that the specific symptoms that parents initially recognize may be associated with the speed with which they receive a diagnosis, and that the saliency of symptoms may be culturally shaped. Environmental, cultural, and socioeconomic factors may also have an impact on whether a parent receives a diagnosis. Implications for professional awareness and increased accuracy of diagnosis are also suggested.

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Introduction

For every childhood problem that receives a medical diagnosis, there is a period of time between a parent's first recognition of an unusual behavior and the eventual diagnosis. Researchers have examined this period from multiple perspectives. In some cases (e.g. McMiller & Weisz, 1996; Chung et al., 1999; Howard & Hodes, 2000), researchers describe how this sequence varies within a culture across ethnic groups, while other researchers (e.g. Ho & Chung, 1996) aim to understand how it may vary within a culture across different health concerns. Each step of this process can serve as a window into broader factors. For example, the saliency of different symptoms sheds light on shared beliefs about deviance as well as knowledge about normative development. The type of medical professionals, healers, family members, or others sought out for consultation illuminates underlying aspects of a cultural explanatory model (Kleinman, 1980), as well as highlights how

economic factors influence both the nature of the help available and the amount that is possible. The time between symptom recognition and diagnosis is also often focused upon because it constitutes a specific period during which earlier diagnosis may lead to faster intervention.

In the field of autism, a driving force behind research on how symptoms are recognized and diagnosed has been the understanding that earlier treatment can lead to a more positive outcome. While much about the course of autism is still unclear, the importance of early intervention for such children is almost universally acknowledged (National Research Council, 2001; Klinger & Dawson, 1996; Powers, 1992). For example, Powers (1992) notes the advantage of intervention before maladaptive patterns of behavior and communication are firmly ingrained, and that early intervention has significant benefits for parental mental health, such as maximizing family acceptance and adjustment to their child's disability. Early intervention programs also have an impact on child functioning, often leading to full inclusion programs in elementary school (Dawson & Osterling, 1997). Further evidence for the critical

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importance of early intervention is provided by studies contrasting the effects of later intervention—significant differences in improvement for children who begin a program before the age of 5 as compared to those who begin after the age of 5 (Fenske, Zalenski, Krantz, & McClannahan, 1985). Clearly, the operative philosophy behind intervention for autism is to intervene as quickly as possible.

Yet treatment relies on accurate diagnosis, and this must begin with a family member or caregiver's ability to identify problematic behaviors. Accordingly, studies have focused on the age of the child and specific symptoms of autism recognized by parents. In a study on mothers' perception of age of onset, mothers identified autism earlier than ADHD, conduct disorder and ADHD comorbid with conduct disorder, with average age of recognition at 15 months (Sullivan, Kelso, & Stewart, 1990). Abstracted record reviews in two studies found the average age of recognition to be 14.9 months (Volkmar, Stier, & Cohen, 1985) and 18.3 months (Siegel, Pliner, Eschler, & Elliott, 1988). Most recently, DeGiacomo and Fombonne (1998) found the average age of symptoms arousing concern was 19.1 months using the Autism Diagnostic Interview (Lord, Rutter, & Le Couteur, 1994), a standard diagnostic tool for autism (1998). These studies suggest that parents first notice differences in their children fairly early, given the complexities of actual diagnosis.

Recognition of a problem is only the first step of the process, however, and diagnosis of autism continues to create considerable confusion in actual practice. Prominent researchers have argued that "there is no other developmental or psychiatric disorder of children (or, perhaps, of persons of any age) for which such well-grounded and internationally accepted diagnostic criteria exist" (Cohen & Volkmar, 1997, p. 947). Regardless of the clarity of diagnostic criteria in standard systems such as the Diagnostic and Statistical Manual (DSM-IV; American Psychiatric Association, 1994) and International Classification of Diseases (ICD-10; World Health Organization, 1992), actual diagnosis requires not only the knowledge that the symptom is associated with the disorder (i.e. a familiarity with diagnostic categories) but also a belief that the symptom is problematic. At the stage of diagnosis, this can present difficulties. If, for example, a professional does not regard delays in language as atypical until a late age, then a child presenting at an earlier age with this feature may not be "picked up" even by a professional with knowledge of Western diagnostic standards. Professionals' adherence to standard guidelines such as DSM and ICD may also vary as a result of numerous factors, including interpretation of symptoms and the perceived relevance of criteria (Fryers, 1986).

Furthermore, unlike Down's syndrome or a sensory or motor impairment, there are no obvious physical

markers of autism. The diagnosis of autism often is as much an evaluation of the absence of certain behaviors as the presence of others (Lord, Storochuck, Rutter, & Pickles, 1993; Richer, 1996), increasing the difficulty of identification. For example, the absence of appropriate interaction with peers, an important feature of the disorder, is often attributed to a personality trait of the child rather than recognized as a deficit. Romanaczyk, Lockshin, and Navalta (1994) note that the uneven skill development characteristic of autism may further hinder diagnosis by making a child's overall functioning appear higher because of a few specific abilities. In some cases, the saliency of a characteristic of autism may not be fully observed until the child is put into a new environment. It is often the case that social difficulties may not be evident until a child has the opportunity to interact with peers, or that a child's fixation with routine may not become clear until he is placed in a structured environment that does not allow for his own patterns.

The research literature has provided a general understanding of the way the recognition of symptoms leads to diagnosis, and the benefits of early diagnosis, but an obvious gap remains in the work of both autism researchers and that of medical anthropologists. To date, autism researchers have almost entirely neglected families of diverse ethnic backgrounds and those in non-Western countries, and medical anthropologists have virtually ignored the condition of autism. This lacuna in the research literature exists even though the pervasive developmental disorders have been identified in at least 80 countries worldwide and autism offers researchers a remarkably rich topic for research (Daley, 2002). To address this gap, the current study focuses on autism in the urban areas of one particular non-Western country: India.

Autism in cultural context: India as a case study

Of all the developing countries in which autism has been described, India has by far the largest literature on the disorder. Over 50 articles and chapters on infantile autism have appeared in Indian publications and by Indian authors since 1962. The quantity of literature available from India is intriguing when one considers that several researchers have claimed that autism in places such as India is either rare or nonexistent (Sanua, 1984; Lotter, 1980) or if present, then not reported. For example, Lotter begins a paper by stating that "the literature on the syndrome of childhood autism contains no descriptions of cases occurring amongst the indigenous populations of developing countries" (Lotter, 1978, p. 231), when in fact, by 1978, there were at least 12 published accounts by Indian authors.

While the literature suggests that medical professionals maintain a variety of beliefs and practices, no single view of autism that emerges from within India.

Autism has been called childhood schizophrenia as early as 1959 (Batliwalla, 1959) and as recently as 1987 (DeSousa & DeSousa, 1987). A chapter by an authority on child mental health emphasized the presence and role of psychosocial stressors in the etiology of autism (Kapur, 1995); however, other recent articles have suggested biological explanations (Kar, Khanna, & Kar, 1997). Additional terms used to describe the disorder include infantile autism, early infantile autism, savant syndrome, childhood psychosis, pervasive developmental disorder, and disintegrative psychosis. A complete review of this literature is beyond the scope of the paper, but it is clear that Indian researchers themselves believe autism to be a worthy area of study, and this body of literature provides an excellent historical picture of the evolution of beliefs, diagnosis, and treatment of the disorder within India.

An examination of autism in India may also allow a preliminary focus on certain aspects of the disorder. For example, if it is true, as prominent Indian psychologists have suggested (e.g. Kakar, 1981; Sinha, 1988), that Indians largely emphasize conformity to social norms and value social relatedness, then a disorder that is primarily one of social relatedness may have special significance. The family of a person unable to perform these roles may be more affected by the disorder than a family in a culture with less social emphasis, and parents might recognize social symptoms earlier. In addition, Indians “know” autism: Western psychiatry and psychology were imported during colonialism, and medical practitioners routinely diagnose the condition, thereby placing the disorder of autism on the Indian map, historically, medically, and politically (Daley & Sigman, 2002). In addition to documenting the process of symptom recognition and diagnosis of autism in India for the first time, the second goal of this paper is to suggest that the particular combination of parent factors and professional beliefs does not necessarily result in a linear process of symptom recognition, help-seeking and diagnosis by a medical or mental health professional. Data from interviews with parents of autistic children and the qualitative portion of a survey about the diagnosis of autism among professionals will be used to suggest factors within the Indian context that may have an impact on different stages of the diagnostic process.

Method

Sample

Data for this study were collected from 95 families located in four major metropolitan cities in India: Kolkata, Bangalore, Chennai, and New Delhi. Informants consisted of 43 mothers, 24 fathers, two other

relatives, and 26 families where both parents participated equally in the interview. Sixty percent of the households were nuclear families, 32% were extended (e.g. included family members beyond the nuclear family) and 7% were joint families (e.g. included two separate households sharing a common space). The offspring with autism at the time of the interview ranged in age from 2 years 10 months to 27 years 6 months with an average age of 10 years, and all families had one or more children diagnosed as autistic by an Indian medical or psychological professional. Fifty-four percent of the children had some functional language, as defined by flexible use of phrase speech with a range of abilities within that grouping. Eighty children were male, 18 were female (three families had more than one child with autism). There were no differences between cities in the primary informant, the age or sex of the child at the time of the interview. Table 1 presents background information.

Fourteen families in the sample first received a diagnosis of autism from outside India, (in the United Arab Emirates, Kuwait, Bahrain, Holland, the UK, and the US) and for five of these families, the diagnosis received abroad was also their only diagnosis. Data from these 14 families are included in the analyses of initial symptom recognition, but the five families whose first and only diagnosis came from abroad are excluded from all analyses related to initial diagnosis.

Because diagnosis was a primary focus of the study, recruitment of families through any type of medical route (whether “allopathic,”¹ or otherwise) was strictly eliminated. Instead, families were recruited through special schools for children and adults with mental disabilities. The main source for locating special schools was a national directory of facilities published by the National Institute of Mental Handicap, and supplemented with school names from other directories, recommendations by parents, school officials, and physicians. Because not every school (special and typical) within a given city could be visited due to time and logistical constraints, an effort was made to select schools of different sizes, locations, and affiliations, at which children from different backgrounds might be present. The choice to recruit through schools clearly involves a bias, since it remains unknown (but assumed) that many families have children who attend no formal school at all, and that many of these are of lower class and income. However, schools appear to provide the most representative sample of families who *have* received a diagnosis of autism, particularly given that special

¹ Allopathic is a term commonly used by Indian physicians to refer to the conventional route of medical training and practice, in contrast to schools offering Ayurvedic, Homeopathic, and other training.

Table 1
Background of participants

	<i>N</i>	%
<i>Sex of child with autism</i>		
Male	80	81.6
Female	18	18.4
<i>Family setting</i>		
Nuclear	57	60.0
Extended	31	32.6
Joint	7	7.4
<i>Birth order</i>		
Only child	36	37.9
First born	26	26.3
Second or later born	36	35.8
<i>Religious background</i>		
Hindu	77	81.1
Muslim	3	3.2
Christian	11	11.6
Other	4	4.2

attention was made to sampling a range of schools within a given city.

A standard procedure was followed in obtaining children from schools. Schools were contacted ahead of time by phone or mail and given information about the study. Once at the school, the researcher determined which children had received a diagnosis of autism and observed all classrooms to locate children who were autistic but may not have a recorded diagnosis in the file, reviewed school charts and files, and interviewed teachers and administrators. Parents were contacted by phone, mail, or in person. The researcher explained that the goal of the study was to better understand families and children with autism in India, particularly the process of obtaining a diagnosis and services. Participants were assured that their child's school would not know whether or not they ultimately chose to participate, and no families declined to participate. The researcher then scheduled a time to visit the family in the home.

Parents of children who did not have a diagnosis of autism on file but exhibited any signs of autism were also contacted, and asked whether they had ever received a diagnosis of any kind for their child. If the parent responded that they had received a diagnosis of autism, these families were also eligible for the study. Diagnoses made solely by teachers, family members, and non-professional school staff were excluded primarily because a main focus of the larger study was to examine the path to diagnosis within the allopathic and Western model. However, this was not a significant exclusionary criterion, as only three of all the children observed had

received a diagnosis from a teacher but no other professional.

Additional confirmation of autism was not attempted in this study for two primary reasons, one methodological and one theoretical. At the time of the study, no Western autism rating scales or checklists were in use with Indian children. While it may be the case that the presentation of autism does not differ markedly between Indian children and their counterparts in the US and elsewhere, the confirmation of the reliability of these diagnostic scales with Indian children warrants a separate study, and therefore these scales were intentionally not used to avoid confounding the research question with a separate, methodological issue. Secondly, because the primary objective of this study was to understand the process of help-seeking from the perspective of parents who *believed* their children were autistic as a result of a diagnosis already received, whether the child did in fact meet criteria for autism according to the DSM-IV criteria was of secondary importance.

Procedure

Parents

Background information was collected and in-depth, semi-structured interviews were conducted in the home, and all interviews were conducted in English. The time spent with each family lasted between 1½ and 5 h, which included breaks and interruptions, with an average of just under 3 h. Children were observed at home and at school, and in numerous cases, the interviewer accompanied families to other settings, such as the market, temple, restaurants, and other family members' homes. While not truly ethnographic, these visits provided additional opportunities to talk with parents and other family members about their experiences. The general flow of questions began with the pregnancy and birth of the child and traced the pathway from birth through current services. In addition to the specific questions about symptom recognition, help-seeking and diagnosis described below, parents were also asked about their children's current level of functioning, their concerns about and expectations for their children, their knowledge of autism and belief about the cause, and all treatment or interventions they had received.

The researcher obtained specific information regarding symptom recognition and diagnosis, the first unusual behavior perceived, the age of the child at that time, and the sequence of allopathic professionals consulted. All responses were recorded verbatim. Parents were then asked about their help-seeking behavior, including the names and professions of those consulted, what they were told by professionals, and the name of any diagnosis, date, and professional giving the diagnosis.

Diagnostic information was verified through parent copies of reports whenever possible.

Professionals

The data obtained from parents are supplemented by comments made on a survey received from 165 psychiatrists, 95 psychologists, and 677 pediatricians. Psychiatrists and psychologists were obtained through a random sampling of the most current directories of the national organizations of these professions in India, and pediatricians from contacting the entire membership directory. Foreign members of all three associations were excluded from the sampling. Participation of psychiatrists and psychologists was anonymous; as part of the awareness study, pediatricians were asked to include their names but were assured that all information would remain confidential.

The response rate was 23% for psychiatrists, 46% for psychologists, and 7% for pediatricians. One reason for the low response rate among pediatricians may have been that a stamped envelope was not included for this group as was with the other professions. In addition, irregular mail delivery and outdated addresses resulted in the return of approximately 300 pediatrician surveys.

The complete survey included three parts: background information, open-ended questions, and a list of 18 characteristics or behaviors of autism modified from Stone (1987). This list of characteristics includes those required by the third edition of Diagnostic and Statistical Manual (DSM-III), as well as characteristics associated with other disorders (e.g. hallucinations, hyperactivity, and allergies). Respondents were asked to check which items were *necessary* for a diagnosis of autism, which items were *helpful but not necessary* in a diagnosis of autism, and which items were *not helpful* in a diagnosis of autism. The results of diagnostic criteria are presented elsewhere (Daley & Sigman, 2002). In the current study, responses from the two open-ended questions: “what other comments do you have about your experiences with autism in India?” and “what other behaviors or characteristics do you use in guiding your diagnosis?” are used to complement data from parents.

Results

Initial symptom recognition

The first step in the process of seeking a diagnosis is the recognition that some aspect of development is not proceeding as expected. Parents in the current study reported that they first noticed something different when their child ranged in age from 3 months to 6 years, 5 months of age ($M = 25.7$ months, $SD = 12.8$), in contrast to studies conducted in the West finding recognition between 14.9 and 19.1 months (DeGiacomo & Fombonne,

1998; Volkmar et al., 1985). No difference was found for age of recognition based on sex of the child. In addition, no difference was found for age of recognition based on birth order; contrary to parents' explanation that they did not notice symptoms sooner because they lacked experience with child development, later-born children were not recognized as having difficulties any earlier than first-born children.

To analyze the behaviors that caused concern initially, responses from the semi-structured interview were coded into eight categories. Inter-rater reliability for coding of the first symptom noticed yielded a kappa of 0.80, falling into the range of strong agreement (Landis & Koch, 1977). Responses were then collapsed into five broader categories: social difficulties, speech and language, typical autistic behaviors, behaviors not specific to autism, and medical or developmental difficulties. Half the parents reported noticing just one behavior, although as many as six different symptoms were identified by parents ($M = 1.84$, $SD = 1.09$). A total of 137 symptoms or behaviors were reported, since some parents described simultaneous concerns in multiple domains. Forty-five percent of the parents noticed social difficulties first, such as a lack of interest in people, poor eye contact, not playing with other children, general social incompetence, withdrawing from family members, or the sense of being “in a world of his own,” a phrase that was repeatedly used by parents. The second most common symptom to raise concern was a delay in speech or limited speech (31.6% of the families), often described as “less speech.” An additional 13.3% of parents noticed deviance in speech, rather than a delay. Following these areas, 25.6% of parents noticed behaviors not specific to autism, such as crying, destructive behavior, and problems with sleeping or eating, and 23.3% of parents noticed medical or developmental difficulties, such as a delay or regression in milestones, seizures, being “slow,” and having an unusual posture or gait (see Table 2).

There were no differences in symptoms first noticed based on sex of the child. In addition nine parents reported that they were unaware of anything unusual about their children until a doctor, teacher, family member, or neighbors brought it to their attention.

While causal relationships cannot be inferred, the information about the very first symptom recognized does suggest that subsequent diagnosis may be influenced by the saliency of the initial symptoms. Using only the *first* initial symptom described by parents, significant differences were noted between groups. Parents with concerns about medical problems (e.g. seizures) or delayed development recognized a difference first, at an average of 15.5 months, and post hoc Tukey tests showed that this difference was significantly earlier than parents noticing behaviors not specific to autism, $F(4,85) = 4.38$, $p < 0.05$. However, these parents took

Table 2
Initial symptom recognition and mean ages

First symptom noticed	N (families)	%	Mean age	SD
Social difficulties	39	44.5	25.5	12.7
Social difficulties	32	35.6	24.8	12.9
Eye contact	8	8.9	25.3	13.9
Speech and language	42	44.9	25.8	9.3
Delay in speech, limited speech	31.6	31.6	23.2	6.9
Deviance in speech	12	13.3	31.9	11.8
Behavior not specific to autism	22	25.6	28.5	18.3
Behavior not specific to autism	17	18.9	28.8	20.3
Activity level	6	6.7	26.5	11.1
Medical/development problems	21	23.3	18.7	11.7
“Autistic-type” behaviors	13	14.4	23.7	7.8
Total ^a	137		24.4	12.0

^aTotal is more than 95 families and 100% because of multiple responses.

significantly longer to receive a diagnosis of autism than all four other groups, $F(4,73) = 4.45$, $p < 0.005$, taking an average of 59.4 months ($SD = 56.8$). Children whose parents recognized a medical problem first were, on average, *two years older* at their initial diagnosis than children whose parents recognized other behaviors. In contrast, children whose parents reported noticing typical autistic behaviors (e.g., hand or finger mannerisms, unusual play with toys, repetitive or stereotyped use of objects) received significantly more diagnoses on the Pervasive Developmental Disorders (PDD) spectrum than children whose parents reported all other symptoms first, $F(4,85) = 3.99$, $p < 0.005$. As explained by a pediatrician who runs a private clinic, “even though I might have seen autistic children, they were brought to me by their parents for some other problem, like respiratory or gastrointestinal problems and in our busy schedule in a semi-urban area we concentrate on the problem for which the child is brought.”

In the current sample, examples of variation in the interpretation of symptoms were plentiful. One father considered his 3-year old “mature,” because although she completely ignored children her own age, she responded well to adults. A mother explained that she had not been alarmed when her son was still not speaking at age 4 because, as she noted, “it is well known that the Indian boy child speaks late,” while other parents referred to older siblings or other relatives who “only said ‘ama’ at 6 years.” Also, related to language impairments, an 8 year old with no speech and repetitive forms of play was termed a “dull-headed boy” by his father, a general medical practitioner, who believed the problem would be outgrown by 11 or 12 years of age. These beliefs can help explain why parents

may wait as long as two and a half years before seeking professional help for the first time. Of course, it is also possible—and perhaps even likely—that parents consult family members, religious leaders, friends, and others prior to a pediatrician, psychologist or other professional, and this information was difficult for parents to remember clearly.

Help-seeking behavior and diagnosis

What happens between parental recognition of symptoms and diagnosis? This process varied considerably in the current sample. Upon sensing a difference in their child, parents often wait to see whether it may resolve on its own. In the current study, parents waited as long as 2 years and 8 months ($M = 7.15$ months, $SD = 7.64$) before seeking help from a medical professional, although a sizeable group of families (27%) reported visiting a professional immediately upon suspecting that something was wrong. Boys were taken for consultation significantly later than girls, $t(90) = 2.1$, $p < 0.05$, although no differences between the sexes were observed for other factors such as the age at diagnosis, time spent seeking help before diagnosis, or number of diagnoses.

Including only the 81 families who received their first diagnosis within India, the average age of the children at the time of their first diagnosis on the PDD spectrum was 4 years, 11 months, with a range from 1 year, 3 months of age all the way to a teen who received her first diagnosis at the age of 19 years (excluding this teen, the average age at diagnosis was 4 years, 9 months). Parents spent an average of 24.1 months ($SD = 27.1$ months) between the time they initially took their child to a

doctor and their initial diagnosis of autism. The older a child is at initial diagnosis, the fewer diagnoses of autism he has, $r(87) = -0.30$, $p < 0.01$, which may be because older age at diagnosis is associated with greater help-seeking (as indicated by number of doctors consulted), $r(85) = 0.43$, $p < 0.01$, and thus parents finally have a satisfactory answer. This may also be true because diagnosis becomes clearer with age, or as a psychiatrist explained, “in India children with autism or autistic behaviours are seen rather late and hence the diagnosis is not very difficult.” Parents reported seeing an average number of 3.5 doctors before receiving a diagnosis, although 18 of the children were seen by six or more professionals before receiving a diagnosis, and children in this study received an average of almost two diagnoses on the PDD spectrum ($M = 1.97$, $SD = 1.19$) each. The actual number of consultations is likely much higher, as some parents could not recall the exact sequence and number of doctors seen.

Professionals providing the diagnosis of autism were primarily psychiatrists and psychologists. Of the diagnoses related to autism, 28.5% were made by a psychiatrist and 26% by a psychologist. An additional 23% were made by a team of two or more medical professionals working together. Of note, an additional 21% of diagnoses came from pediatricians and neurologists, two professions that commonly refer to specialists for diagnosis (Table 3).

Table 3
Professionals (specialties and sub-specialties) providing Autism/PDD diagnoses

	N	%
Psychiatrist	56	28.5
<i>Psychiatrist</i>	29	14.8
<i>Child psychiatrist</i>	23	11.7
<i>Neuropsychiatrist</i>	4	2.0
Psychologist	51	26.0
<i>Psychologist</i>	47	24.0
<i>Child psychologist</i>	3	1.5
<i>Neuropsychologist</i>	1	0.5
Neurologist/neurophysician	21	10.7
<i>Neurologist</i>	16	8.1
<i>Child neurologist</i>	5	2.6
Pediatrician	21	10.7
<i>Pediatrician</i>	12	6.1
<i>Neuropediatrician</i>	9	4.6
ENT	1	0.5
Team of two or more	45	23.0
General practitioner	1	0.5
Total	196	100

One psychiatrist noted somewhat bitterly that “parents run around with general practitioners, neurologists and other specialists, but do not come to psychiatrists. These people are not able to direct to the proper agency.” Because actual names of physicians were obtained from parents, it is possible to determine that these 196 diagnoses were made by just 63 individual physicians and 6 facilities.

The families visited a number of national centers. National medical facilities are found throughout India, but perhaps the most well-known hospitals are the National Institute of Mental Health and Neurosciences (NIMHANS), located in Bangalore, and the All India Institute of Medical Sciences (AIIMS) in Delhi. Thirty-seven families in the current study sought help from NIMHANS, including six families from New Delhi, 13 from Kolkata, and 18 from Bangalore. Twenty-four children actually received a diagnosis from NIMHANS. Of the 24 diagnoses, only six were the first diagnosis received, suggesting that parents are referred to NIMHANS for a second opinion rather than seeking out the institution on their own. Among the 13 children who were not given a diagnosis at NIMHANS, the most common reason was that a diagnosis of autism had already been received and therefore it was not necessary to do an additional exam. In contrast, none of the 14 children seen at AIIMS, Delhi received a diagnosis of PDD or autism, regardless of its location in the help-seeking process.

This study only included children who had received a diagnosis of autism at some point in their life, but the diagnosis of autism or PDD was far from the only diagnosis they had been given. Past diagnoses were obtained from both records and parents' report, and where information was available from both, the written diagnosis was used. These 219 diagnoses were coded into 12 categories, with very high inter-rater reliability of 0.99 achieved on 20% of these diagnoses. The most common incomplete diagnosis was that of just mental retardation with no mention of autism, in 53 of the diagnoses. It is possible that all of these cases did, in fact have mental retardation (as is true in 50–75% of children with autism) but it is also clear that in many instances, the autism is overlooked. It appears that the standard diagnostic procedure when mental retardation and autism are both present is to diagnose mental retardation as primary. One psychologist noted that, “in severe mental retardation, we generally do not give diagnosis of autism, we just call it ‘M.R. with autistic features’” and a frequent comment from professionals, was that autism is “very rarely diagnosed and often missed; it is mostly misdiagnosed as mentally retarded.” In addition to mental retardation, children in this study received other diagnoses, including hyperactivity, a psychological, emotional or psychiatric problem, and a physical or nutritive problem (see Table 4).

Table 4
Non-autism diagnoses

Diagnosis	N	%
Mental retardation, cognitive impairment	53	24.2
Attention and Hyperactivity problems	43	19.6
Psychological or psychiatric problem	24	11.0
Physical or nutritive problem	22	10.0
Epilepsy or seizure disorder	15	6.8
Learning problem	12	5.5
Behavioral	11	5.0
Speech or language	10	4.0
Minimum brain damage/dysfunction	9	4.1
Delayed development, delayed milestones	8	3.7
Hearing problem	5	2.3
Other	7	2.8
Total	219	100

One other important factor to consider is the historical context of the current study. Just as diagnostic procedures have become more refined in the West, they have also developed in India. Even excluding two older children who were not taken for consultation until over 6 years of age, parents of children under 12 years are now taking their children for help sooner than in years past, at an average of 28 months as compared to 35 months for parents of children over 12 years of age, $t(88) = -2.3, p < 0.05$. The length of time spent searching for a diagnosis was also significantly shorter for children under 12 (19 months as compared to 34 months), $t(81) = -2.2, p < 0.05$. Lastly, children under age 12 at the time of the interview had received significantly more diagnoses on the PDD spectrum, $t(96) = 2.16, p < 0.05$, suggesting that the younger group of children have benefited from increased awareness among professionals over the past decade.

Discussion

This paper has described the process of parental recognition, help-seeking behavior and initial diagnosis among parents of autistic children in urban India. These data from India indicate that parents notice something different about their child between 6 and 10 months later than has been found for parents in the US. This is not wholly due to lack of experience with developmental norms, since there were no differences between first born and later born children. However, it is clearly not possible to determine from these data whether symptoms actually appear later in children in India than in the West.

Parents recognized a range of symptoms as problematic, with a large percent of the families noticing social difficulties first. The social impairment of young children

with autism can, indeed, be distinctive in some cases, while may be more subtle in others. One explanation for the sensitivity to social behaviors in particular is the emphasis on social relatedness within traditional Indian culture, in which mothers and very young children have a “protracted intimacy” (Kakar, 1981, p. 108). The child-rearing style of Indian mothers has been described as indulgent and protective (Saraswathi & Pai, 1997). Thus mothers who demand social-emotional closeness may be alerted to the unusualness of an aloof child, while their need to protect the child may lead them to dismiss or deny signs of problematic behavior. Saraswathi and Pai (1997) as well as others (e.g. Sinha, 1988) have also described a shift in this parental behavior toward demanding more adherence to social behaviors and obedience.

Norms about child development are clearly culturally shaped and have an impact on when a symptom may be recognized as problematic and what symptoms are noted. A psychologist explained this relationship:

there is confusion in understanding smiling responses and aloofness. Quietness and non-responsiveness of infants to human beings is mistaken. A child that keeps quiet, without emotions, keeps to oneself is interpreted as a good child. Parents are proud of such children because they are trouble-free.

Describing this phenomenon more generally, a psychiatrist noted that the low rate of diagnosis may not necessarily be a misinterpretation of symptoms, but that “there may be a tendency by our rural mass to accept and tolerate some degree of abnormality as normal.” Of course, the current sample centered not on parents in the rural areas, but those in the urban areas. Still, parents may notice symptoms later as a result of different standards for problematic behavior, a phenomenon that is consistent with the adult distress threshold model described by Weisz (1989) and colleagues.

Differences in diagnosis were observed in children whose parents recognized different symptoms. Children with medical problems were taken to doctors earlier, but it appears that their autism was initially overlooked, as they did not receive earlier diagnoses. In contrast, parents who went to physicians with complaints about the most classically autistic symptoms received more diagnoses of autism. This finding suggests that professionals are aware of autism, but may either rely only on parents’ report to guide their diagnosis, may not understand the spectrum nature of the disorder or may not recognize more subtle symptoms. Parents also spent an average of 2 years between the time they began looking for help and received their first diagnosis. In conjunction with the finding that pediatricians and neurologists are also involved in diagnoses, these different aspects of help-seeking support the need for

more awareness of diagnostic criteria among professionals, especially the importance of screening for pervasive developmental disorders.

In the current sample, diagnoses were elicited from multiple professionals, including psychologists, psychiatrists, and pediatricians, indicating a fairly high level of help-seeking behavior. The tendency for Indians to shop around for health-related concerns has been previously noted (e.g. Chaturvedi & Malhotra, 1982; Dhillon & Srivastava, 1986; Nunley, 1996), and was commented on by professionals in the current study, as well. One psychiatrist noted, “parents remain perturbed, disturbed, feeling helpless and frustrated, running from doctor to doctor and trying faith healing and alternative medicine in between.” Indeed, this is very much what the parents themselves described, as they went from “pillar to post” in search of a doctor who could provide a diagnosis, an explanation, and perhaps also compassion. As one mother explained, “we need kind, smiling doctors because we’re already in such agony.”

One important environmental consideration in the process of help-seeking and diagnosis of autism in India is whether a facility or physician capable of diagnosis exists in any given area, and the extent to which parents must travel. India is 2000 miles from North to South, and 1200 miles from east to west—a calculation that does not include the Northeast states which are located on the eastern side of Bangladesh. Some families in the current study managed to travel considerable distances for consultation: 13 families from Kolkata traveled 1881 kilometers to Bangalore, and six families from New Delhi traveled the 2061 kilometers. Because the standard mode of transportation is by rail (and none of these families traveled by air), these trips take days rather than hours. Thus, the environmental constraints of geography in a country such as India on health practices are considerable, particularly in combination with cultural and economic factors.

An important cultural factor that ultimately may effect whether parents receive a diagnosis is the degree to which they feel compelled to seek out the most prominent doctors in their area. Doctors around the world have a privileged status, but in India, doctors are often viewed as “next to God.” In Hofstede’s (1980) description of high power-distance cultures such as India, the emphasis is largely on the expert role of the professional; Indian researchers have referred to the “omnipotence with which doctors are imbued” (Varma, Kala, & Deodhar, 1981, p. 109). When going through the list of doctors they had visited, parents often described physicians with characterizations such as “a well-respected doctor,” “the most famous doctor in Kolkata” “a very famous person,” “one of the foremost doctors in India, internationally acclaimed” “one of the top guns in neurology” “a leading psychiatrist in Bangalore,” “very famous,” “he’s

one of the best in Asia.” Nuneley (1996) notes that this image may be reinforced by psychiatrists seeking to claim their own place in the medical system and who care greatly about “recognition, respect, and prestige” (176).

However, there are no requirements for professionals in India to keep their skills and knowledge up to date, and Joshi (1992) notes that the field of clinical psychology does not even have formal licensure or certification, let alone a continuing education program. Many professionals may stay informed through conferences and journals, but if not, professionals trained more than 20 years ago may still adhere to the conceptualization of autism that was present at that time. In fact, in a study of general practitioners in India, younger doctors were found to have a significantly better understanding of mental illness than older doctors (Gautam, 1974). Therefore, these older and “well-respected” doctors may have an outdated view of autism and this may explain some of the late or misdiagnosed cases in the current study.

Although it has yet to be documented empirically, there is no question that socioeconomic factors also influence whether a child in India receives a diagnosis of autism. This may be a result of at least two related factors: a different pattern of help-seeking because of limited financial resources and lack of awareness and misconceptions of physicians. To begin with, there is a prevalent belief in India that families of lower socioeconomic background and less education are not as sensitive to developmental difficulties and may not “pick up” the symptoms as readily. A psychologist attributed the predominance of higher SES patients to “the higher level of education of this group and thus greater awareness of norms for children.” A psychiatrist pointed out that parents may “acknowledge [autistics] perhaps as crazy maybe due to poor intellectual development” but that

the diagnosis of autistic disorder does not affect people in low socioeconomic status, since it is yet another handicap to be dealt with. It affects the middle class families as they find the diagnosis difficult to accept.

Another psychologist interpreted lower sensitivity to symptoms as related to social class, in the observation that “most of the families seen are upper middle or upper class because they have the time to think about the problems and also those are the ones who can afford it.”

Whether or not recognition of developmental problems occurs later in certain groups, lower income and less educated families are also more likely to attend a subsidized or free large government facility, where, as a pediatrician explained, “since it is an over crowded

government general hospital, many of the children with autism are missed.” In the current study, families were all middle to upper class, and it is quite likely that this is indeed because lower income families are less likely to receive a diagnosis; for example, two lower income children at a large government school were identified as autistic based on their behavioral presentation, but their records indicated only a diagnosis of mental retardation from a government hospital outpatient department.

Physicians may not provide a diagnosis for numerous reasons. Lack of awareness of diagnostic criteria is clearly one possibility: in the current study, children were given not only diagnoses of autism, but also a range of mental, behavioral, and physical conditions. In some cases, these other diagnoses may reflect actual comorbid conditions, but in some, it may be indicative of a physician’s lack of knowledge. For example, the 677 pediatricians participating in the survey on beliefs about autism retained many outdated notions about the disorder. A third endorsed that autism is more common among high socioeconomic status families and is caused by cold, rejecting parents, 60% believed that emotional factors play a major role in the etiology of autism and half agreed that most autistic children will “outgrow” autism (*Action for Autism, 2000*).

However, low levels of diagnosis may also occur because until recently—and even still in many parts of the country—receiving a diagnosis of autism did not result in any different course of intervention or education than did a more general diagnosis of mental retardation. The value of a diagnostic label in the West is its ability to communicate information and facilitate treatment, but in India this has not been the case. A pediatrician emphatically described this scenario by noting, “Alas, when we do decide to evaluate a child and treat him, specialists in child psychology, speech therapy, etc. are so few that even teaching institutes in North India do not have them. So WHERE DO WE GO?!” Similarly, another pediatrician explained that “in private practice it is a difficult job. Most of the parents do not cooperate with private practicing doctor for a language follow-up and assessment and most of the doctors feel unrewarded to diagnose and work up such cases.” In addition, physicians may intentionally not provide a diagnosis because they do not believe parents will understand, such as a psychologist who lamented, “telling the parents is very difficult because they have no idea about the term,” and another who remarked that it is “difficult to communicate about the disorder to the parents.” Motivation among professionals to diagnose should therefore be included as an influence on whether a child receives a diagnosis or not.

The data presented in this paper describe a process that is only the beginning of a much longer road—that of raising a child with autism in a vastly different landscape of disability than in developed countries.

Achieving a diagnosis of autism, as these parents have, brings their experience closer to their Western counterparts, but perhaps in only limited ways. With the exception of children attending one of the few special programs for children with autism, the educational programs for children diagnosed with autism did not differ from those for these children diagnosed with mental retardation. For a few children, a diagnosis of autism closed doors to educational opportunities rather than opening them, when stereotypes and misconceptions about “violent” and unmanageable children with autism were present. Some families described years of inappropriate medication, painful separations from family members, and constant worry about an uncertain future.

What, then, did the diagnosis of autism achieve? For many parents, it provided a network of other families, and renewed energy and optimism. For some, it provided a purpose, as they took over the responsibility of their child’s education. As one father explained,

What’s wrong with calling a suitcase a suitcase? The medical term is autism, so as a parent, I must be bold enough and strong enough to say “yes, my son has autism” and not be deceived in any way by some religious name like saying “he’s on the chosen path.” If I had not gone to another psychiatrist, how would I know the real problem? Telling parents—right or wrong, crude or sophisticated—now I have found the information I need.

This father was active in his child’s school and is similar to many parents of a younger generation of children, since the experiences described through the data above are a process that is constantly changing. In the past 6 years, alone, there have been major gains achieved by the national autism society of India, Action for Autism. There is now greater awareness among professionals and the public, legislation to protect and support children with autism, teacher training courses, parent empowerment through parent groups, and international collaboration. Just one example is a survey and information packet sent by Action for Autism to over 10,000 pediatricians in India detailing criteria for diagnosis and possible referrals. None of this has been instigated or organized by professionals, but by parents who had received a diagnosis of autism for their child. Just as diagnostic practices in the West have evolved over the past several decades, so too have practices in India. With increased access to updated information through sources such as the Internet, it is likely that patterns of help-seeking and diagnosis in India are likely to change more rapidly in the coming years than they have during the lives of many of the children in the current study.

Western academics may be tempted to decry the reification of western diagnostic systems in a setting such

as India, and clearly, there is room for improvement in criteria even for a disorder as globally recognized as autism. Yet the autism movement within India depends on an increase in correct diagnosis of autism to further the tenuous gains achieved so far. Before legal recognition of autism as a disorder in 1999, children with such a diagnosis were ineligible for the concessions allowed to parents of children with other disabilities, and schools specially designated for children with autism were denied federal funding on the grounds that autism was not legally recognized as a disorder. Now that autism has been legally recognized, the government of India has placed the onus on the parent-driven autism movement to demonstrate why children with autism should receive education or intervention that differs from a mentally retarded child without autism. Therefore, in contrast to the West, receiving a diagnosis of autism for many of the families in the study may not have resulted in earlier intervention or a better outcome than had they received a later diagnosis or none at all. Still, it is facile to say that nothing was gained by the diagnosis. Just by virtue of having received a diagnosis of a disorder that legally did not even exist, these children and families became part of a historical movement that may ultimately result in children with autism receiving the advantages of early intervention and education that families in the West enjoy.

Several limitations of the current study warrant mention, in addition to those already noted throughout this paper. The sample obtained in this study is linked to the issue of who has access to the professionals such as the pediatricians, psychiatrists, and psychologists who were largely responsible for diagnosis. This paper has attempted to highlight the apparent reality that lower income families both may lack access to specialists and may not be given the diagnosis of autism because of professionals' beliefs about their ability to understand or use such a diagnosis. It is possible, for example, that a family residing in a Delhi slum could have reached a large government hospital, less likely that they would receive a diagnosis, and extremely unlikely that they would send their child to even the largest and least expensive special school, since even many non-disabled slum children do not attend school. Thus, these results cannot be generalized to lower income families. Focus on these relatively prosperous families should not be interpreted as discounting the significance or impact on poorer families, nor should it be taken as reification of the notion that autism does not affect the lower class. Rather, the sample selected reflects the reality of diagnosis and treatment of autism in urban India today. As increased awareness spreads among all Indians, it is naturally hoped that future research can examine families representing a broader range of socioeconomic status.

It is also worth noting that a single interview, even one lasting a whole afternoon, is unlikely to uncover many subjective aspects of the process of diagnosis. While

families participating in this study were quite forthcoming with their experiences, the depth and range of experiences would naturally be enhanced by a truly ethnographic study of Indian families with autistic children. In the same vein, all interviews were conducted in English. Since English was the preferred language for many families, this did not cause a problem in those cases. However, in some families, using English may have restricted the amount less-fluent mothers could communicate fully with the researcher. Conducting the interviews in English creates an obvious bias and limits the possibility for culturally nuanced information to be obtained. In some cases, however, the presence of an Indian translator may have caused discomfort for parents, who described having felt self-conscious about being judged by an "insider" such as neighbors and relatives who did not understand the disorder. Future researchers may want to weigh the pros and cons not only of the choice of interview language, but perceived insider/outsider status of the researcher.

In conclusion, this paper has outlined the path from initial symptom recognition through help-seeking among the allopathic system of medicine and eventual diagnosis for parents of autistic children in India, and has reviewed possible factors that may influence whether a parent actually receives a diagnosis. Many of these observations deserve further investigation and hold the potential to accelerate this process. If researchers can understand the barriers to receiving a diagnosis that exist at multiple levels of analysis, then parents of autistic children yet to be diagnosed have much more to look forward to as the refinement of the diagnostic process changes the landscape of disability within India. Ultimately, the journey from recognition of an initial problem to the diagnosis of autism may serve as a key to future opportunities for parents in non-Western countries, rather than merely as an isolated event in a child's developmental history.

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