

# Diagnostic Conceptualization of Autism Among Indian Psychiatrists, Psychologists, and Pediatricians

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Diagnostic criteria for autism and background characteristics used by 937 Indian psychiatrists, psychologists and pediatricians were examined. Participants were asked to rate 18 behaviors as *necessary* for a diagnosis of autism, *helpful but not necessary*, or *not helpful* in a diagnosis of autism, and were asked to provide other information about their experiences with autism. Professionals' experience with diagnosing cases did not vary by profession and, in general, the three professions agreed about the characteristics most necessary for a diagnosis. However, within-group differences were found on the agreement over the usefulness of individual characteristics and amount of experience diagnosing cases as autistic. Comparisons with *DSM-III* and *DSM-IV* criteria suggest that Indian professionals may adhere to these systems. Conclusions about diagnosis in a cultural context and areas for future research are suggested.

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**KEY WORDS:** Indian psychologist; autism; autism diagnosis; diagnostic conceptualization.

## INTRODUCTION

Although autism is considered to have among the most clearly defined diagnostic criteria of any childhood disorder (Cohen & Volkmar, 1997), the extent to which these criteria are followed by researchers and clinicians may vary widely across cultures. It is well-accepted that cultural factors are likely to effect the definition and recognition of symptoms, if not also treatment and course (Berry, Poortinga, Segall, & Dasen, 1992). This may be especially true for autism, a disorder for which the diagnostic criteria have changed even in Western countries. Although reports of the pervasive developmental disorders have emerged from a variety of developing and nonindustrialized countries, diagnostic criteria often are not mentioned, thus limiting the conclusions that may be made about

autism. The overall aim of the current study is to understand how professionals within one country, India, utilize Western criteria in the diagnosis of autism.

Understanding how a group of professionals conceptualizes the diagnostic criteria of autism is critical to understanding the broader context of the disorder. First, diagnosis has obvious implications for treatment recommendations (McConachie, 1995). Gilliam and Coleman (1982) note that beliefs about cause are likely to dramatically affect models of treatment in autism. For example, a professional who perceives poor mother-child attachment as a primary characteristic of autism is likely to recommend psychotherapy or parent counseling as an intervention. In a country with limited services available as well as limited access to information about treatments, parents may be more bound to the recommendations and referrals made by their diagnostician. Diagnosis therefore becomes the "key" to treatment.

Second, diagnostic procedures often hold significant political and social ramifications (Sturmev & Sevin, 1994). In the United States, defining autism as a set of behavioral symptoms with a biological basis in

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the 1960s and 1970s carved out a field of research, spawned a national organization, and helped shape laws that are in effect today. Highlighting commonalities and exploring differences in diagnostic procedures may clarify specific areas for intervention at the professional level (Stone, 1987), including both training of professionals and laws to delineate eligibility for services and concessions. In a country without a well-formulated policy or legal guidelines concerning autism, such an investigation may have even greater significance.

There has been a paucity of studies on diagnostic beliefs and practices of diagnosis of autism conducted in developing countries. Together, China and India comprise 35% of the world's population, yet practically nothing is known of diagnostic practices of autism in these countries. India is a country of over 1 billion people and is poised to become the world's most populous country within the next few decades (Cohen, 2001); currently, India alone accounts for 21% of the world's population growth. Under the assumption that autism is a population-based disorder, even the conservative estimates of 4 to 5 persons in 10,000 affected by autism indicate that there are a staggering half-million people in India with the disorder. Other prevalence estimates (e.g., Gillberg, Grufman, Persson, & Themner, 1986), indicate there may be as many as 2 million people in India with autism.

In addition to its population, India is also a developing country with an unusual wealth of literature on autism and current activity in the field, making it extremely appropriate for a study of diagnostic concepts. Over 50 articles and chapters on infantile autism have appeared in Indian publications and have been written by Indian authors, dating back to 1962. Publications from the past decade have included more specification of diagnostic criteria than in previous years, yet the picture is far from clear; among these publications, less than half included a definition or explanation of criteria used to diagnose subjects, and of these, there was no single predominant system. Thus, a fundamental question arising from this diverse body of literature is simply, what do Indian medical professionals believe autism is?

The current study seeks to answer this question. Segall, Lonner, & Berry (1998) state that the goals of cross-cultural psychology are tri-fold: to test existing knowledge of a particular construct in other cultures, to investigate the subject of study without imposing any bias, and to integrate these two to further overall understanding of the subject. The goals of cross-cultural psychology as a whole can be applied to the goals of the current study. The first aim is to describe the background characteristics of three groups of professionals

who are likely to diagnose autism in India: psychiatrists, psychologists, and pediatricians. The second goal is explore how these professionals conceptualize the diagnosis of autism by illuminating the specific criteria they use for diagnosis of autism, including those characteristics and beliefs not widely used in the West. The third goal, by highlighting the above areas, is to provide a synthesis of professional beliefs about autism and propose areas for future investigation.

## METHOD

### Participants

A total of 937 Indian professionals (165 psychiatrists, 95 psychologists, and 677 pediatricians) participated in this study through a direct mail survey. Respondents were recruited in two ways. Results from psychiatrists and psychologists were obtained by random sampling of the most current directories of the national organizations of these two professions in India, the Indian Psychiatric Society (IPS) and the Indian Association of Clinical Psychologists (IACP). The method for obtaining results from pediatricians differed in that all pediatricians who were members of a national organization, the Indian Association of Pediatricians (IAP), were sent a letter inviting them to participate in an awareness raising project conducted by the Autism Society of India, Action for Autism. 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. No remuneration was given for participation, although all participants were informed that they could receive a copy of the results if they wished. In addition, pediatricians who responded were sent a packet of brochures about autism and other related information as part of the awareness campaign.

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. Given the uniqueness of this project, no figure exists for acceptable rates of survey return within India. However, a comparable survey among members of the American Psychiatric Association on the causal agents of autism achieved a response rate of 16%

(Gallagher, Jones, & Byrne, 1990). Therefore, the response rates obtained were considered satisfactory for a direct mailing in this setting.

### Materials

The survey comprised three parts. The first section asked participants to answer a number of questions about their background and experiences with autism. These questions included degrees held and universities from which they were received, the number of years in practice, the location of their current practice, the approximate number of children who had received a diagnosis of autism, and the approximate total number of clients with autism seen. Psychologists and psychiatrists were also asked the average length of time for an assessment and fees charged. Pediatricians were asked about referrals and recommendations they typically made for clients with autism.

The second part of the survey consisted of a list of 18 characteristics or behaviors of autism developed by Stone (1987). This list of characteristics includes those required by the *Diagnostic and Statistical Manual, 3rd edition (DSM-III)*, American Psychiatric Association, 1980), as well as characteristics associated with other disorders (e.g. hallucinations, hyperactivity, 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 are *not helpful* in a diagnosis of autism. Although the option of *not helpful* was an addition to the original Stone survey, this option was provided to avoid the implication that these criteria are indeed a part of the disorder. These three categories were considered mutually exclusive and responses with multiple selections were discarded.

The third part of the survey asked respondents to answer two 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?" Space was provided for each of these, and participants were encouraged to attach additional sheets if necessary. The survey was written in English.

### Design and Procedure

Respondents were asked to fill out both sides of a survey and return the form to the experimenter at an Indian address. A self-addressed, stamped envelope was included to facilitate responses for psychiatrists and psychologists.

## RESULTS

### Respondents Characteristics

Participants came from all parts of India, with predictably higher representation from the southern region (36%), where there is a higher concentration of medical facilities and practitioners. Of the remaining areas, 17% of the participants were from the north, 21% were from the west, 14% were from the east, and 12% were from the central region. A chi-squared test revealed no significant difference in area of origin between the three groups. This representation is generally reflective of the distribution of each profession in India for the northern and southern regions; however, respondents from the central region are underrepresented for all three professionals and the east is over-represented for psychologists and pediatricians. About 59% of the professionals indicated that they worked in a hospital, about 50% in private practice, and about 53% in another setting.

Participants had a range of professional and educational experiences. The mean number of years of practice for the sample as a whole was 14.9 years ( $SD = 9.9$ ). A one-way ANOVA revealed no significant difference in the number of years of experience by profession. Psychiatrists and psychologists both reported an average of 16 years of experience, whereas pediatricians had an average of 14.5 years (respective SDs are 10.2, 10.6, and 9.7). The sample included participants with a number of different degrees and combinations of degrees. Psychiatrists generally had an MBBS (the basic medical degree), an MD, and a Diploma in Psychiatric Medicine. The majority (81%) of the psychologists held a MA, and 55% also held a PhD. Thirty percent of psychologists also held Diplomas in Medical and Social Psychology, and 35% held a Masters' in Medical and Social Psychology. Pediatricians almost universally completed the MBBS. A large percentage (69%) of the pediatricians also held an MD, and 60% had a Postgraduate Diploma in Child Health. Thirty-one professionals indicated that they had received training or a degree from outside India and were excluded from all subsequent analyses.

### Experience With Autism

A one-way ANOVA yielded no significant differences between professions in the number of people with autism seen. Although not a significant difference, psychologists reported having seen the most cases, with a mean of 23.4 cases during their career, whereas pedi-

atricians reported a mean of 20.7, and psychiatrists a mean of 16.2 (SDs = 39.4, 93.1, and 24.7, respectively). A subset of 16 respondents reported seeing considerably more people with autism, numbers that were more than 3 SDs from the mean. A one-way ANOVA excluding these outliers revealed a significant difference between professions in number of cases seen  $F(2, 844) = 6.12, p < .002$ . Post-hoc Tukey tests revealed that psychologists ( $M = 21.6, SD = 40.0$ ) reported seeing significantly more cases of autism than pediatricians ( $M = 10.5, SD = 30.5$ ), with psychiatrists still falling between these groups ( $M = 16.1, SD = 24.6$ ). However, the median number of cases seen may be a more telling statistical gauge of experience than the mean; the median cases reported was 8 cases psychiatrists, 10 cases for psychologists, and 3 cases for pediatricians.

A one-way ANOVA also revealed no significant difference between professions in number of cases diagnosed. Analyzing all subjects, pediatricians report the most cases diagnosed ( $M = 13.5, SD = 58.0$ ), followed by psychiatrists ( $M = 12.4, SD = 41.1$ ) and psychologists ( $M = 11.0, SD = 17.9$ ). When excluding cases lying more than 3 SDs above the mean, this pattern changes and psychologists report having diagnosed the highest number of cases ( $M = 8.8, SD = 10.8$ ), followed by psychiatrists ( $M = 7.8, SD = 12.6$ ) and pediatricians ( $M = 6.5, SD = 16.9$ ). However, the difference in number of cases diagnosed is not statistically significant. Median figures for number of cases diagnosed illustrate that the majority of professionals surveyed may have less experience than these means suggest, with a median of 3 cases for psychiatrists, 5 for psychologists, and 1 for pediatricians. All further analyses related to number of cases seen or diagnosed were made excluding the outlying cases.

To examine the relationship between the number of people reportedly seen, number of cases diagnosed and length of practice, Pearson product-moment correlations were performed. An overall association between

number of years of experience and number of people with autism seen was found only for the pediatricians. For pediatricians, the number of people seen  $r(616) = .105, p < .01$  and diagnosed  $r(608) = .147, p < .01$ , were both positively associated with the number of years of experience.

### Criteria for Diagnosis

Professionals were asked to rate whether each of 18 characteristics was *necessary* for a diagnosis of autism, *helpful but not necessary*, or *not helpful*. One-way ANOVA revealed a significant group effect for the choice of all three categories,  $F(2, 892) = 36.13, p < .000$  for *necessary*,  $F(2, 892) = 16.47, p < .000$  for *helpful but not necessary*, and  $F(2, 892) = 7.10, p < .000$  for endorsement of *not helpful* (see Table I for means and comparisons). Post-hoc independent *t*-tests revealed that pediatricians were more likely to rate a characteristic as *necessary* than were psychiatrists,  $t(288) = -8.406, p < .0001$  and psychologists,  $t(733) = -4.936, p < .0001$ . Psychologists were more likely to endorse items as *helpful but not necessary* than were psychiatrists  $t(250) = -2.109, p < .05$  and pediatricians  $t(733) = 5.076, p < .0001$ . Finally, psychiatrists were more likely to endorse items as *not helpful* than either psychologists,  $t(250) = 2.214, p < .05$  or pediatricians,  $t(801) = 3.745, p < .0001$ .

Of the three options presented to the professionals, the category of *necessary* provides the clearest information about what symptoms or characteristics are most likely to yield a diagnosis of autism. One way to approach the central question of this study, the diagnostic conceptualization of autism, is to look at which characteristics professionals view as necessary or essential for diagnosis of the disorder. When characteristics are ranked in order of respondents' selection as necessary, it is possible to compare across groups to see if professionals globally agree on the relative importance of characteristics in a diagnosis of autism.

**Table I.** Means, Standard Deviations and One-Way Analysis of Variance (ANOVA) of Endorsement of Category

Category	Psychiatrists		Psychologists		Pediatricians		ANOVA	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>F</i> (2, 892)	<i>p</i>
Necessary	5.14	2.45	5.42	2.68	7.04	3.00	36.13	.000
Helpful but not necessary	6.39	2.68	7.15	2.91	5.55	2.80	16.47	.000
Not helpful	4.34	2.39	3.66	2.28	3.55	2.40	7.10	.000

Using this ranking procedure, a considerable amount of agreement was found across professions. The same six items were most often endorsed as necessary for psychiatrists and psychologists, and five of the six of these were the same for pediatricians. The characteristic endorsed most frequently as *necessary* by all three professions was lack of social responsiveness. The other top five characteristics most often endorsed as *necessary* were need for sameness/resistance to change in routine, lack of eye contact, onset of symptoms before 30 months of age, and peculiar speech characteristics. The only variation across professions was that language delays were considered more important to pediatricians than to the other two professions, ranking fifth for this group, compared with seventh for psychiatrists and eleventh for psychologists. Table II presents a comparison of characteristics ranked as *necessary* by the three professions.

In addition to this ranking procedure, other methods of assessing overall consensus among professionals were followed. One way to approach this involves looking at how much the agreement for a given item differs from the maximum possible agreement, for example, from either total endorsement or no endorsement at all within the category of necessary. To measure the agreement on a particular choice, the absolute value of the difference between the percent of professionals choosing a characteristic and 50% was calculated for each characteristic for the three professions. For example, an “agreement” score of 50% indicates total agreement, or that 0% of the group disagreed. Percentages closer to 0 indicate maximum disagreement. Using this method, the pediatricians have the greatest disagreement amongst themselves on which characteristics are necessary, with an average disagreement of 22.0%, followed by psychologists (24.5%). Psychia-

**Table II.** Percent Rankings of Characteristics as Necessary for Diagnosis of Autism (by Profession)

Psychiatrists			Psychologists			Pediatricians		
Rank	Item	%	Rank	Item	%	Rank	Item	%
1	Lack of social responsiveness	83.5	1	Lack of social responsiveness	71.3	1	Lack of social responsiveness	81.4
2	Need for sameness, resistance to change in routine	70.6	2	Lack of eye contact	69.1	2	Lack of eye contact	81.2
3	Lack of eye contact	66.9	3	Rigid or stereotyped play activities	60.9	3	Rigid or stereotyped play activities	74.0
4	Onset of symptoms before 30 months	64.2	4	Need for sameness, resistance to change in routine	52.7	4	Need for sameness, resistance to change in routine	71.3
5	Rigid or stereotyped play activities	60.1	5	Onset of symptoms before 30 months	50.0	5	Language delays	69.7
6	Peculiar speech characteristics	50.9	6	Peculiar speech characteristics	44.6	6	Onset of symptoms before 30 months	63.6
7	Language delays	43.8	7	Unusual mannerisms such as finger flicking	31.5	7	Peculiar speech characteristics	54.3
8	Unusual mannerisms such as finger flicking	22.9	8	Attention deficits	31.2	8	Attention deficits	46.5
9	Mutism	17.3	9	Unusual sensory responses	30.0	9	Mutism	46.0
10	Attention deficits	15.2	10	Mutism	27.2	10	Sudden, unexplained mood changes	38.0
11	Unusual sensory responses	14.6	11	Language delays	25.0	11	Unusual mannerisms such as finger flicking	37.6
12	Inappropriate laughing or giggling	11.8	12	Inappropriate laughing or giggling	19.8	12	Unusual sensory responses	32.4
13	Sudden, unexplained mood changes	7.8	13	Sudden, unexplained mood changes	14.8	13	Inappropriate laughing or giggling	28.1
14	Thought disorder	5.8	14	Thought disorder	14.0	14	Thought disorder	27.8
15	Hyperactivity	3.8	15	Hyperactivity	12.1	15	Aggressive behavior	21.5
16	Aggressive behavior	2.6	16	Aggressive behavior	7.7	16	Hyperactivity	17.0
17	Hallucinations	1.9	17	Hallucinations	5.7	17	Hallucinations	3.2
18	Allergies	0	18	Allergies	0	18	Allergies	1.7

trists have the least overall disagreement on which characteristics are necessary for a diagnosis (30.5%).

A second approach is to use the agreement score method to examine which of the 18 characteristics cause the most disagreement among professionals. When examined by characteristic, there is no clear pattern of which item creates the most disagreement of whether it is necessary. For psychiatrists, the three characteristics with the least agreement are peculiar speech characteristics (.9%), language delays (6.2%), and rigid or stereotyped play activities (10.1%). For psychologists, the three characteristics causing the most disagreement are onset of symptoms before 30 months (0%), need for sameness and resistance to change in routine (2.7%), and peculiar speech characteristics (5.4%). For pediatricians, the top characteristic of disagreement is attention deficits (3.5%), followed by mutism (4.0%) and peculiar speech characteristics (4.3%).

To compare response patterns between professions, chi-squared tests were run. For 15 of the 18 characteristics, clear group differences exist between professions. Of the 18 characteristics, 13 were significant at the  $p < .0001$  level, and the additional 2 characteristics were significant at the  $p < .001$  and  $p < .05$  level. The three characteristics for which the groups did not differ significantly were peculiar speech characteristics, lack of social responsiveness, and allergies, indicating that professionals responded to these items in a consistent manner across the groups.

Although not the primary intention of this paper, it is interesting to examine how Indian professionals' use of diagnostic criteria compares with the *DSM-III* criteria, from which the items were taken, and the more current *DSM-IV* (APA, 1994) criteria. In the *DSM-III*, the five characteristics designated as primary, or necessary for the diagnosis of autism are language delays, onset of symptoms before 30 months, lack of social responsiveness, need for sameness and resistance to change in routine, and peculiar speech characteristics. More than half of the Indian professionals endorsed these characteristics as *necessary*, however, there were also notable differences. In addition to the low endorsement of language delays discussed above, psychologists differed from the guidelines of both the *DSM-III* and *DSM-IV* in that only half endorsed onset of symptoms before 30 months as *necessary*. Professionals also did not overwhelmingly endorse peculiar speech characteristics as *necessary*. Indian professionals indicated high endorsement of lack of eye contact and rigid or stereotyped play, characteristics which are currently part of the *DSM-IV* criteria. An additional characteristic that is part of the *DSM-IV*, unusual mannerisms, was nominated by about

a third of the professionals as *necessary*. Other characteristics that are neither part of the *DSM-III* nor *DSM-IV* were also endorsed as *necessary*, primarily by pediatricians. Percent endorsement as *necessary* compared with *DSM-III* and an approximation of *DSM-IV* criteria is presented in Table III.

In addition to the general comparisons based on group membership, exploratory analyses were used to determine whether experience with diagnosing autism, as measured by number of reported cases diagnosed, was related to endorsement of items as *necessary*. Three groups were formed based on the reported number of people diagnosed: a no-experience group, consisting of professionals who report diagnosing no clients with autism ( $N = 298$ ), a moderate-experience group, with professionals reporting 1 to 10 diagnosed cases of autism ( $N = 432$ ), and a high-experience group, with professionals reporting 11 or more diagnosed cases of autistic ( $N = 127$ ).

Examining the endorsement of category choice revealed no significant difference in use of the category *necessary* based on number of cases diagnosed. Surprisingly, a one-way ANOVA showed the high-experience professionals identifying significantly more characteristics as *helpful* but not *necessary* than the groups with less experience  $F(2, 864) = 11.86, p < .01$ . This finding is consistent with a correlation performed between number of reported diagnoses and number of criteria considered *necessary* for diagnosis. This correlation revealed a significant inverse relationship,  $r(883) = -.075, p < .05$  between number of cases diagnosed and number of items endorsed as *necessary*; in other words, the more cases a professional reports to have diagnosed, the fewer characteristics the professional reports as *necessary* for diagnosis.

Ranking of respondents' choices as *necessary* when grouped by experience revealed a similar pattern as when ranked by profession, with the same six characteristics appearing as the most *necessary* in a diagnosis. Notably, the high-experience group agreed slightly *less* than the moderate- and no-experience groups that these characteristics are *necessary*; for example, lack of social responsiveness was the characteristic rated as highest by all three experience level groups. Only 78.6% of the high-experience group rated this characteristic as *necessary*, compared with 80.6% of the moderate-experience group and 83.3% of the no-experience group. For this comparison, the characteristics falling at the bottom of the list of *necessary* characteristics are also interesting, particularly for the high-experience group. Sizeable minorities identified characteristics as *necessary* that are not typically required for a diagnosis of

**Table III.** Endorsement of Characteristic as Necessary for Diagnosis of Autism Compared with *DSM-III* and *DSM-IV*

Characteristic	DSM-III	DSM-IV	Combined (%)	Psyctr (%)	Psycog (%)	Pedtrn (%)
Language delays	P	Y	60.5	43.8	25.0	69.7
Onset before 30 months	P	Y	62.3	64.2	50.0	63.6
Lack of social responsiveness	P	Y	81.4	83.5	71.3	81.4
Need for sameness, resistance to change in routine	P	Y	69.2	70.6	52.7	71.3
Peculiar speech characteristics	P	Y	52.6	50.9	44.6	54.3
Lack of eye contact	S	Y	77.3	66.9	69.1	81.2
Mutism	S		38.6	17.3	27.2	46.0
Unusual mannerisms	S	Y	34.3	22.9	31.5	37.6
Unusual sensory responses	S		28.8	14.6	30.0	32.4
Rigid or stereotyped play		Y	70.1	60.1	60.9	74.0
Attention deficits			39.1	15.2	31.2	46.5
Sudden, unexpected mood changes			30.3	7.8	14.8	38.0
Inappropriate laughing or giggling			24.1	11.8	19.8	28.1
Thought disorder			22.2	5.8	14.0	27.8
Aggressive behavior			16.5	2.6	7.7	21.5
Hallucinations			3.2	1.9	5.7	3.2

*Note.* Psyctr = psychiatrist; Psycog = Psychologist; Pedtrn = Pediatrician; P = primary characteristic; S = secondary characteristic; Y = yes.

autism: 29.8% of the high-experience group identified thought disorder, unusual sensory responses, and mutism as *necessary*, 26.1% identified inappropriate laughing or giggling, 20.7% cited hyperactivity, and 17.8% cited aggressive behavior.

**Free Response Criteria and Comments**

To elicit comments about the use of criteria not included on the original survey, and other comments on professionals’ experiences, respondents were provided space to include any other behaviors, characteristics, or information they used in a diagnosis. Over half (55%) of the psychiatrists, 71% of the psychologists, and 38% of the pediatricians offered other characteristics they consider useful in making a diagnosis of autism. Approximately three-fourths of both the psychiatrists and psychologists and 15% of the pediatricians provided additional comments. To analyze these items, qualitative data analysis techniques were used. Initially, each response was broken down into the smallest meaningful unit or single characteristics. This process yielded a total of 1471 criteria or characteristics and 766 comments. From a review of these items, categories were established to capture the different ideas represented. This coding scheme was pilot tested on a random selection of

items and was revised into 19 categories for criteria and 10 broad categories for comments. Two raters independently coded the criteria. Interrater reliability for coding these additional characteristics using Cohen’s Kappa, was .83 and interrater reliability for the comments was .86. Landis and Koch (1977) categorized kappas in the range of .80 to 1.0 as having the greatest strength of agreement.

Overall, more than half (60.2%) of the additional responses fell under the three main areas for diagnosis of autistic disorder appearing in the *DSM-IV* and *ICD-10*: qualitative impairment in social interaction; qualitative impairments in communication; and restricted, repetitive, and stereotyped patterns of behavior. The category with the most spontaneous mention was social interaction (24.1%), distinct from eye contact (1.8%), which is consistent with the professionals’ endorsement of lack of social responsiveness as the most necessary characteristic in diagnosis. Language use, language delay, communication, and imagination combined resulted in 16.8% of the additional comments. Apart from social interaction and autistic-type behaviors (17.5%), no other single category was endorsed by more than 7.0% of the participants who listed additional criteria.

The remaining additional characteristics can be characterized either as associated features of autism or as characteristics not typically used in a diagnosis based

on *DSM-IV* criteria. These associated characteristics are development (4.6%) and cognitive ability (6.0%) and some of the characteristics in behaviors not specific to autism (4.4%), although some of the characteristics in this category are not typically associated with autism. The characteristics not typically associated with autism are appearance (3.1%), background (4.5%), psychological factors (3.6%), medical variables (2.6%), exceptional abilities (1.2%), and medical and psychological factors (6.2%). In addition, diagnostic tools and practices (7.6%) provide information about the process and techniques used in diagnosis. A detailed list of these additional criteria, and of additional comments, may be obtained from the first author.

In contrast to the extra criteria provided, comments made by professionals covered a range of topics and opinions, not only related to diagnosis. Comments were coded into 10 broad categories: awareness (10.2%), characteristics and definition (16.2%), cultural factors (2.2%), diagnosis (16.4%), experience (11.5%), family related (9.2%), incidence (5.4%), referrals and professional aspects (8.5%), treatment (18.3%), and project related (2.1%). Because of the complexity of responses, some comments received multiple codes. This process resulted in a total of 1039 codeable items.

The comments related to awareness fell into awareness among three groups of people: parents or family members, the general public, and professionals. Most referred to poor awareness or a tendency by parents to ignore or not understand problems, the need to educate people to facilitate early diagnosis, and lower than adequate levels of awareness and poor training among professionals. The comments about the definition and characteristics of autism were extremely varied, ranging from specific features of the disorder to beliefs about cause. Relatively few comments noted cultural factors; those that did included mention of the tolerance of families, misinterpretation of symptoms, treatment, family structure, and other areas related to culture.

Diagnosis and issues surrounding diagnosis were a popular topic of note. Related to the ease or difficulty of diagnosis, about 80% of those surveyed noted that diagnosis of autism is difficult, whereas the remainder felt it was not difficult. Comments about specific diagnostic tools and facilities centered on the lack of these, with other comments noting disorders considered in differential diagnosis. Underdiagnosis was frequently noted, although a few professionals believed the disorder is overdiagnosed in India. Comments about misdiagnosis included many different disorders for which autism may be mistaken and how typical misdiagnosis may be.

Roughly half the comments about experience were anecdotes about personal experiences the professionals felt were relevant; the other half expressed that they felt their experience was limited. Comments about family included both those about personality traits or characteristics of the parents as well as parental attitudes, ways of handling children, family support, and acceptance of the disorder. About two-thirds of the comments on the incidence of autism referred to autism being a rare disorder, compared with only a handful feeling it is not rare. The remainder of comments on incidence noted in what socioeconomic background it was most likely to occur and other related factors.

Respondents' comments on professional aspects included the presenting problems seen in practice, referrals typically made to other professionals, and the need for more research. Comments on the treatment of autism covered a range of topics. Many professionals felt that treatment was difficult or challenging, particularly owing to a lack of facilities or schools. Opinions on the use of medication were mixed. Professionals typically noted that prognosis was poor, but insufficient follow-up may make it difficult to ascertain completely. A few professionals noted the importance of parent education and treatment as an effective intervention for the child. Last, a number of professionals requested additional information about autism as a result of having received the survey.

## DISCUSSION

Variation in beliefs about diagnosis of autism should come as no surprise to those familiar with the field. The change in diagnostic criteria in the West through the years has been well-documented (Sturme & Sevin, 1994). However, the current study is the first to examine diagnostic practices and beliefs about autism in a non-Western context, illuminating variation in these beliefs among psychiatrists, psychologists, and pediatricians in India. Differences between groups would not be wholly unexpected, yet, in general, the three different professions have a similar impression of the disorder, one of which emphasizes the social deficit in autism (lack of social responsiveness, lack of eye contact) and highlights the rigidity and restricted interests that are common (rigid or stereotyped play activities, need for sameness and resistance to change in routine).

Compared with the guidelines in the *DSM-III*, the source originally used to devise the survey, and the more current *DSM-IV*, two main findings emerge. First, Indian professionals largely agree with the character-



istics considered primary in *DSM-III*, although of the three groups, fewer psychologists endorsed all five of these traits as *necessary*. Secondly, Indian professionals endorsed two other characteristics as *highly necessary*: lack of eye contact and rigid or stereotyped play. These two traits are now a part of the *DSM-IV*, suggesting that Indian professionals may be following these criteria. Respondents also endorsed characteristics that were not highlighted in either version, such as attention deficits, sudden unexpected mood changes, inappropriate laughing or giggling, and thought disorder. One explanation for the saliency of these characteristics is that they reflect the actual presentation of the children brought for assessment. Eighteen percent of parents asked what the first symptom they noticed in their child noted their child's activity level or other behaviors not specific to autism, such as destructive or aggressive behavior (Daley, unpublished data 1999). In addition, cultural norms that suggest a lower level of activity or unusual behavior as acceptable (Kumar, 1988) may sensitize professionals to these characteristics when present in a child with autism.

A finding related to diagnostic criteria is that professionals in India do not seem to consider language disturbances central to the disorder. Psychologists, in particular, ranked language delays lower in usefulness than characteristics such as mutism, attention deficits, and unusual sensory responses. Pediatricians, on the other hand, ranked language delays after the social and behavior characteristics listed above. One explanation for the relative lack of emphasis on language delays is provided anecdotally. The belief that "the male Indian child speaks later" was expressed by several parents of autistic children interviewed about their child's diagnosis (Daley, 1999). Some professionals may also follow the guideline that Indian children speak single words by 1 to 1.5 years of age, but that speech should not be considered delayed until the child is 3 years old (Kumar, 1988). An additional reason language delay is not as widely relied on for diagnosis may be that language delays are not specific to autism and, therefore, not considered as helpful.

Even excluding the professionals reporting outlying numbers of cases seen and diagnosed, the findings of this study suggest that professionals with different levels of experience may use different criteria to diagnose autism. This includes disagreement over the importance of characteristics such as hyperactivity and aggressive behavior, behaviors that one may not necessarily expect to be used by the more "expert" professionals at all. One explanation for these findings is that lacking experience, a professional relies on a stan-

dard book definition, and it is possible that these brief synopses may be similar across training experiences. If this is the case, it may explain why professionals with more experience use characteristics not typically found in a standard checklist, such as inappropriate laughing and giggling; these are characteristics ascertained through experience.

Allowing professionals to provide additional characteristics and comments adds a richness and range of beliefs not captured elsewhere in the survey. Because not all professionals provided additional information and the amount written varied from just a few words to several pages of comments, these comments cannot be discussed using traditional text analysis methods. Despite the limitations of the additional characteristics and comments, they hint at ways in which the concept of autism among Indian professionals may be unique. Examples of these beliefs include the idea that extended families have an ameliorative effect on childhood problems, that Indians may be more tolerant of differences in their children or less aware because of competing concerns over other health problems, that low understanding leads to unrealistic expectations, and that some parents may prefer traditional forms of treatment, such as Ayurvedic medicine, just to list a few. These comments also highlight the areas of disagreement among professionals, such as whether autism is difficult to diagnose, whether it is a common or rare disorder in India, the most effective treatments, the cause of the disorder, and the typical presenting complaints.

The survey format of this study was both advantageous and methodologically problematic. The use of forced-choice questions may have severely restricted the richness of beliefs and behaviors that naturally occur. Although this was partially addressed by the inclusion of space for extra criteria and comments, a weakness in the design was that respondents were exposed to the list of characteristics before being asked to list other behaviors or characteristics they use in diagnosis. It is possible that the respondents were cued to add behaviors of a certain type, for example, those more reflective of *DSM* criteria, than to include other characteristics or behaviors used.

An alternative approach would have been to allow professionals to generate characteristics they themselves used in diagnosis, and then use qualitative data analysis techniques to determine the categories that emerged. This technique may have resulted in a more indigenous conceptualization of autism in India, and would clearly be the appropriate process if respondents had included practitioners of non-allopathic traditions, such as Ayurvedic, Homeopathic, or Unani physicians.

However, the recent literature from India suggests that the *DSM* and *ICD* systems are increasingly in use by psychiatrists, psychologists, and pediatricians, and that they are also the basis for training in the major mental health training facilities (S. Srinath, personal communication, February 17, 1996). Therefore, it seems appropriate to use a symptoms list suggested by Western medicine for the purpose of the current study.

A second major limitation of the current study is that it is not possible to draw conclusions on the overall accuracy of the diagnoses made by these professionals. In both a study by Stone (1987), in which this measure was first used, and a similar study by Gilliam and Coleman (1982), an "expert" group was used as a template or "gold standard" for diagnosis. In a recent important study, Klin, Lang, Cichetti and Volkmar (2000) similarly used experienced clinicians as the basis for comparison in an examination of interrater reliability of *DSM-IV* diagnostic criteria. However, such a distinction is not possible in the current study. Stone (1987) defined specialists as "individuals who had been directly and extensively involved in research or clinical work in autism for a significant length of time (i.e., at least 5 years)" (p. 618). Gilliam and Coleman (1982) considered professionals to be experts in autism if they had either published books or articles on autism or had more than 2 years of experience working in a nationally recognized program for people with autism, and Klin *et al.* (2000) designated professionals involved in the assessment of over 25 patients as "experienced."

These are all culturally relative terms of expertise, however, and although many highly qualified professionals practice in India, there are no standard criteria that can be applied to determine their expertise in the field of autism. Number of cases seen or diagnosed clearly cannot be a criterion for expertise in the current study, because the number of cases one believes to have seen is based on a particular conception of autism, which may or may not be accurate. Research credentials are also not an accurate reflection of expertise, because publication opportunities and support are vastly different in the Indian context. A number of talented clinicians and professionals may not include publishing as part of their activities for many reasons.

In addition, this definition assumes that experience and knowledge increase with the number of years of practice. However, in the dramatically different medical setting of India, a professional may not keep his or her skills and knowledge up to date. 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 in-

formed 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 (Gautam, 1974), younger doctors were found to have a significantly better understanding of mental illness than older doctors.

Future research of diagnostic conceptualizations of autism may benefit from a number of modifications to the methodology used in the current study. In particular, using more subtle techniques of ascertaining the importance of criteria may elicit responses that represent actual practices followed, rather than just theoretical behavior. For example, one technique would be to use several client examples of children and ask professionals to indicate which characteristics they consider the most important in diagnosis of autism in that child. Having professionals list and rank the factors taken into consideration in these vignettes would provide a more applied perspective on the importance of different characteristics, particularly given the movement in the field to recognize autism as a set of behaviors along a continuum (Filipek *et al.*, 1999).

The findings of the current study have implications beyond the boundaries of the Indian subcontinent. In particular, researchers have speculated on the prevalence of autism, and continue to pose the question of whether the incidence of the disorder is rising or if an apparent increase in cases is a result of improved diagnostic practices (Gillberg, Steffenburg, & Schaumann, 1991). In the current study, the reported number of cases diagnosed varied widely and was, in fact, related to the number of characteristics considered in a diagnosis. Based on this information, reports by professionals should not be relied on to estimate prevalence in the absence of verifying the diagnostic criteria used.

The current study does not seek to answer the question of whether Indian professionals use the same diagnostic criteria as their counterparts in the West, nor can it answer the question of whether the disorder appears with similar symptoms throughout the world. Further research may indicate that autism is more, or less, susceptible to cultural influences than those disorders that have already been studied in a non-Western context, and the authors of this article hope that future research will also include indigenous concepts of autism, such as through sampling professionals from the Ayurvedic, Homeopathic, and Unani systems of medicine. Despite the limitations of the methodology in the current study, the results provide an important overview of diagnosis from a country of increasing prominence, both politically and in population. The findings reinforce the im-

portance of examining diagnostic practices of disorders in a cultural context to gain a broader, more comprehensive understanding of complex disorders like autism.

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