

The Need for Cross-cultural Research on the Pervasive Developmental Disorders

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Abstract Research on the pervasive developmental disorders within a cultural context and in developing countries has received limited attention from both the fields of mental health and anthropology. Although autism holds considerable potential for expanding the field of transcultural psychiatry, the bulk of research has consisted of case studies and brief reviews, with few studies undertaking a serious discussion of cultural factors. The current article reviews the literature to date on autism within a cultural context and highlights both rationale and directions for future efforts in this area, drawing from research with 109 families of autistic children in urban India.

Key words autism • cross-cultural • culture • India • pervasive developmental disorder

Once considered rare, the pervasive developmental disorders (PDD) are now recognized as the third most common form of childhood disability. Major collaboration and consistent measures used across research sites in the US have allowed more statistical power through larger sample size, while diagnostic specification of the disorder has improved through the use of a 'gold standard' for research projects (Lord & Risi, 2000). Technology such as functional magnetic resonance imaging (fMRI) has allowed an increased understanding of the way brain function may differ in autistic

populations (Haznedar et al., 2000), and genetic linkage analysis studies have lead researchers to concentrate on specific chromosomes (Collaborative Linkage Study of Autism [CLSA], 1999). Systematic research on pharmacological interventions and comparative treatment approaches are being undertaken, and advances in legislation have dramatically improved funding for research (Tager-Flusberg, Joseph, & Folstein, 2001). In addition, parent groups have begun to organize to fund their own research initiatives and the journal *Autism* has been established to provide an outlet for new research.

In this renaissance of autism research, where does culture fit in? In addition to the World Autism Organization, national organizations for children and families with autism now exist in over 80 countries, suggesting that at least the diagnostic category has traveled around the globe.¹ Given the wide range of cultures in which the disorder has been reported, one would expect to find a rich and extensive international research literature; instead, surprisingly little is known about autism within a cultural context. Although the study of disability in non-Western countries has gained attention as a significant area of research over the past decade (Ingstad & Whyte, 1995; Retish & Reiter, 1999; see also Marfo, Walker, & Charles, 1986), the majority of disability research in non-Western countries has focused on conditions in which disability is an outcome and conditions for which prevention is a relevant topic. Yet the questions asked by disability researchers (e.g. Whyte & Ingstad, 1995) such as how mental and physical impairment are managed in different cultures and how identity is shaped by disability, are equally as intriguing when asked of autism as of deafness or visual impairment. Areas investigated by those interested in mental health in non-Western countries, such as the social consequences and social contexts of mental illness, are as applicable to autism as they are to schizophrenia and depression (e.g. Desjarlais, Eisenberg, Good, & Kleinman, 1995).

Perhaps autism has fallen between the cracks of the disability literature and mental health fields, viewed by one as a problem akin to schizophrenia and by the other as more related to mental retardation. Regardless of the reasons for the scarcity of research, there are valid theoretical reasons to examine autism within a cultural context and exciting opportunities for those who choose to do so. The aim of the current article is therefore twofold: first, to provide an overview of the research to date on autism within a cultural context and second, to suggest rationale and domains of possible study in this area of research based on the author's ethnographic fieldwork in India.

Autism in Cross-cultural Perspective: Terminology and Research to Date

The cross-cultural framework of psychopathology classification by Berry, Poortinga, Segall, and Dasen (1992) provides one system by which autism can be evaluated. This model suggests that psychiatric conditions can be identified as *culturally relative*, *universal*, or *absolute*. Although the position that autism is best considered a culture-bound or culturally relative disorder may seem extreme, early theories about autism included the belief that it was a disorder of the upper class, one caused by distant, 'refrigerator' mothers (e.g. Bettelheim, 1967) – a theory that implicitly suggests economic relativity. Perhaps stemming from this claim, some researchers have extended this hypothesis to the cultural level. For example, Sanua (1984) asserted that 'infantile autism is an illness of modern civilization, and is therefore to be found primarily in countries of high technology, where there is extensive geographical and economic mobility coupled with the dominance of the nuclear family' (p. 163).

At the other extreme, one might ask whether autism is actually a disorder that should be considered 'absolute.' Berry and colleagues (1992) suggest a disorder that is invariant across cultures will most likely have an organic etiology. Although the exact cause of autism is not known, the overwhelming emphasis of current research is on the biological basis of the condition. Experts on autism have asserted, '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). Presumably, such 'well-grounded' criteria are possible because of the consistency of symptoms, reflecting the underlying biology of the condition.

The middle position in this classification scheme would see autism as a universal disorder which – like schizophrenia – occurs in some form in all cultures, though still susceptible to cultural influences in expression and course. To support this position, one can turn to the evidence of national parent organizations in such diverse countries of the world as Namibia, Uruguay, Malaysia, and Serbia. In each of these countries, a constellation of behaviors has been identified that fit those of the disorder known as 'autism,' although the exact degree of fit has not been examined. The moderate middle position appears to be safest in the absence of data suggesting otherwise, although when a richer body of data are available about autism within a cultural context, we may be in a better position to revise this classification.

From an empirical standpoint, the bulk of available literature is in the form of case reports and overviews, with little connection between different lines of research.² Recent research appears to be drawing more

from the international field of autism, such as testing various assessment tools in other cultures, but the hallmark of this body of research still is the use of a cultural sample without any explicit discussion of cultural factors.

Some of the most thorough discussions of sociocultural factors are found in unpublished dissertation research. These studies include validation of an autism checklist in Jordan (Smadi, 1986), an examination of professional perceptions of Chinese American and Euro-American children with autism in California (Shu, 1989), a cross-cultural study of autism in the US and South Korea, (Seu, 1992), perceptions of social competence among Navaho autistic children (Connors, 1993) and parental experiences and concerns among Hispanic families of children with autism (Moreno, 1996). Most recently, Shaked (2001) has provided a comprehensive analysis of explanatory models of autism among the ultra-orthodox Jewish community in Israel. Through interviews with 30 mothers of autistic children, she describes the 'encounter between a law-breaking phenomenon and a law-guided community' (Shaked, 2001, p. 1). Shaked also presents evidence of concurrent use of Western, biomedical systems of medicine and spiritual and religious treatments, delving into the hierarchy of resort of these mothers. In sum, much interesting cultural work on autism has occurred through dissertation research, but has not been published elsewhere.

Another line of research placing autism in a sociocultural context focuses on class factors. Research has repeatedly suggested no differences in the socio-economic backgrounds of autistic and matched samples (e.g. Ritvo et al., 1971) and in population studies (e.g. Gillberg, Steffenburg, & Schaumann, 1991; Steffenburg & Gillberg, 1986). Nevertheless, it appears that social class factors may influence clinical diagnosis. Cuccaro and colleagues (1996) gave school psychologists, speech-language pathologists, and physicians vignettes depicting children with autism and attention-deficit hyperactivity disorder (ADHD) and found that professionals associated autistic children with higher socio-economic status. Focusing on social factors, Gillberg, Schaumann, and Gillberg (1995) examined three Ugandan children with autism born to immigrant mothers in Sweden. One hypothesis for the increased prevalence in this population compared with the general Swedish population was that Swedish men with Asperger's syndrome would be more likely to seek spouses from other countries because of social difficulties within their own culture, and might therefore produce children with autism. Although intriguing, this hypothesis was not supported.

Given the behavioral characteristics of autism, it is not surprising that anthropological approaches have explored the folk concepts of conditions similar to autism. For example, Ellenberger (1968) noted those children known as '*Nit-ku-bon*' or 'marvelous children' in Senegal had many of the

same traits of autism, such as lack of speech and social unresponsiveness. In another early study, Westermeyer (1979) reported that rural Laotians use a category known as '*Samqng Uan*' to describe children who have developmental difficulties such as delayed learning and difficulty getting along with others, in addition to a lack of flexibility and adaptability – characteristics that the author notes map onto the disorder autism. In a slightly different type of cultural case report, Lane and Pillard (1978) describe their odyssey to find the 'wild boy of Burundi,' a child who was reported to have lived in the jungle. After investigation by Lane and Pillard, it became clear that this youngster had not been reared in the wild, as believed, but he did appear to fit the behavioral criteria for autism.

Bilu and Goodman (1997) provide an intriguing examination of autism and religion within the ultra-orthodox Israeli community. The authors describe how this group has adopted the use of facilitated communication (FC), a procedure that theoretically allows an otherwise non-verbal individual to communicate with physical assistance from a facilitator. Within the context of FC, severely impaired children are viewed as an asset, as described by the authors:

Dialectically, the more incapacitated the individual, as reflected in both physical and mental dysfunctioning, the more permeable the bodily screen, which effectively separates normal people from their divine, supernormal source . . . from a mystico-religious perspective, [FC] is an effective tool for bypassing the afflicted body and making direct contact with the pure soul. Through this contact, extraordinary information from otherworldly spheres may be obtained. . . . (Bilu & Goodman, 1997, p. 385)

The authors note that the messages transmitted through autistic children using FC tend to be heavily laden with a moral tenor, such as admonishment to avoid 'evil tongue' and sexual relations with menstruating women. However, the use of FC in this community has not been without controversy; just as claims of abuse have occurred in the US, public outcry over the use of this technique in Israel has also caused the movement to temper their outreach. The extensive analysis of this unusual case by Bilu and Goodman raises many questions about the nature and direction of transcultural research on autism.

A few researchers have attempted a comparative approach or explicitly addressed cultural factors, and more detailed discussion of these studies is warranted. In the mid-1970s, Lotter (1978) visited six countries in Africa with the aim of identifying possible cases of autism and comparing symptoms with a British sample. Lotter concluded that autistic symptoms, particularly repetitive or stereotyped behaviors, are less common in Africa than in Britain, and that autistic children come from a higher social class. A number of Lotter's findings can be explained by methodological factors,

as he comprehensively discussed in a later article (Lotter, 1980). For example, Lotter obtained his sample from institutions for mentally disabled, whereas many African families do not send their disabled children to schools or institutions (Asuni, 1988; Tungaraza, 1994). He also included indices of competence such as demonstrating an ability to complete a formboard, ride a tricycle and eat with a knife and fork, measures of adaptive functioning that may not be relevant to many African children. However, this study is notable for its scope and path-breaking perspective.

In a more recent cross-national study of autism, Probst (1998) addressed child health-related parental cognitions in families with autistic children in Brazil, Greece, Italy, and Germany. Probst asked about causal explanations in addition to beliefs about prognosis, treatment, the relationship between the parent and professional, and how parents cope with the demands of having a child with autism. He concluded that a feeling of 'coherence' among the parents appeared to be an important aspect of adaptation to having a child with autism, and that the needs of parents include expert information about the nature, course, cause, prognosis, and treatment of autism. He also concluded that state and community support would further increase a feeling of coherence and family adaptation. Probst did not match the families between countries on a number of variables that could influence the results, such as parental education, symptom severity or child age; rather, he selected families to reflect variability in these domains – a decision that may limit the accuracy of his cross-cultural conclusions. Nevertheless, the study was intentionally exploratory in nature and is a valuable attempt to isolate cultural factors (in this case, health-related cognitions) and undertake a serious examination of their relationship to other processes in families with autistic children.

In addition to these studies, the handbook by Cohen and Volkmar (1997) includes a chapter on international perspectives of autism, with reports from China, Japan, Korea, and Latin America as well as a number of European countries. Each of these brief sections covers the history of the disorder in that geographic area, diagnosis, treatment, parents associations, national issues, and research if applicable. Similarly, Morgan (1996) includes overviews on adult issues in autism from Chile, India, and Japan in addition to several European countries. These overviews have emphasized the 'nearly universal acceptance' of the standard DSM-IV and ICD-10 classification systems and comparable approaches to treatment (Cohen & Volkmar, 1997, p. 948). However, those clinicians and researchers asked to submit information about the practices in their country were naturally those known by the authors of each volume, and it is possible that they reflect the most Western system of diagnosis and treatment within each country rather than the norm.

The reports from the diverse countries noted speak only to the presence of autism throughout the world, and leave many questions unanswered – perhaps most strikingly, to what degree the clinical presentation of autism is consistent across cultures. The lack of research may reflect the fact that some researchers have assumed that autism is rare in non-Western countries (Egdell & Nikapota, 1991; Varma & Chakrabarti, 1995), or ‘an illness of modern civilization’ (Sanua, 1984, p. 163). Others have claimed that there is little variation in behavioral manifestation of autism (Campbell, 1996) and that it is constant across culture, ethnicity, and social class (Cuccaro et al., 1996). Morgan (1996) has argued that not only are the same behavior patterns seen, but also ‘the problems of the individuals and their families are virtually the same, and the required responses are quite similar’ (p. 9). In effect, ‘why travel to Calcutta to study children with autism if they look no different from children in Chicago?’ Cuccaro and colleagues (1996) have posited a related explanation: because autism is believed to be a neurobiological condition, the non-biological aspects of the condition appear less relevant.

Rationale for Autism Research in a Cultural Context

Despite prevalent assumptions about the universality of autism, there are compelling reasons from both a scientific perspective and more pragmatic and humanitarian concerns to study autism in non-Western countries. For the purpose of discussion, we can use the two extreme positions of autism-as-invariant and autism-as-variant across cultures to demonstrate the significance of research in field. If the assertion that there is little or no variation in the presentation of symptoms is correct, one rationale for studying autism within a cultural context is that autism may be used as a tool to better understand culture. Similar symptomatology would allow for a purer comparison of the contextual factors of the disorder by holding ‘differentness’ constant. From my own fieldwork in India, seven such cultural processes that are directly related to family experiences of the disorder repeatedly emerged, and suggest numerous avenues for research on autism in non-Western countries.

The issues highlighted below draw upon in-depth interviews and observations with 95 families of children diagnosed as autistic in 4 major cities of India: Calcutta, Bangalore, Chennai, and New Delhi. These families were identified through 37 different special schools for children and adults with mental disabilities, and respondents consisted of 50 mothers, 25 fathers, 2 other relatives, and 32 families in which both parents participated equally in the interview. 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. Eighty children were male, 18 were female (three families

had more than one child with autism); 61% of children in the sample were first-born, and 35% of these were only children. The religious background of the sample was predominantly Hindu.

Visits in the home lasted between 1.5 and 5 hours and centered on an in-depth, semi-structured interview in English. In addition to obtaining family composition, background information about the family, and the birth history of the child, the interview covered: (i) initial symptom recognition, the age of the child, and the course of action taken; (ii) help-seeking behavior and diagnosis, for example, what professionals were consulted, both Western and traditional, what parents were told, and what referrals were made; (iii) subjective experiences with professionals and the process of diagnosis; (iv) treatment used, including all schools, medications and other interventions, parent satisfaction with or concerns about services for their children, and for a subset of the sample, use of non-Western treatment; (v) explanatory models of cause, characteristics and treatment of autism; and (vi) parental concerns and future expectations. The suggestions for research in the area of autism are also drawn from ethnographic observations of the children in this study in contexts beyond the home, including their school environment, community, and with extended family. The researcher observed the process of diagnosis in several large facilities, visited special schools in rural areas, visited institutes and hospitals for mentally ill adults, visited both a Muslim *dargah* or shrine for mental health problems and Hindu holy places, attended autism workshops within India, interviewed professionals at different levels about their experience with families with autistic children, observed government lobbying for recognition of autism, and lived with a family with a teenager with autism. Thus, the examples and suggestions listed below draw from ethnography, participant observation, and from interview data.

Awareness and Concepts of Illness

This includes when a symptom is perceived, by whom, and what behavior is noticed first, as well as whether it is perceived as problematic. More broadly, the familiar construct of an explanatory model (Kleinman, 1980) may prove to be a useful tool for obtaining a wide range of pertinent beliefs about perceived seriousness, etiology, course, treatment, and transmission. Explanatory models of autism are likely to vary from culture to culture, depending on beliefs about normative development and the relative value of different behaviors in a culture. As an example of part of this model, the author's research in India found that beliefs about etiology reflected a range of explanations, with no single preferred model of cause, but which included biological, structural or organic factors as well as environmental and psychological explanations (Daley, 2001). In terms of symptom

recognition, identification of a problem behavior occurred an average of seven months later among Indian parents than has been reported in the US, and the most common first symptom of concern was lack of social relatedness.

In addition to recognition, the meaning attributed to a particular symptom is likely to vary. For example, a 1999 study of psychiatric disorders among children in South India found that parents did not initially report concerns about their children and 'it had never occurred to most parents that their children's troublesome ways were anything other than an accepted part of family life, until a researcher came along' (Hackett & Hackett, 1999, p. 226). Similarly, Leonard (1985) reported on a Sri Lankan family who received, and accepted, an explanation of their autistic child as 'a reincarnation of a warrior who had been severely injured in a battle and was rendered dumb until he died' (p. 200). In the India study, parents of a three-year-old described their daughter as 'mature' because she preferred the company of adults to children, and a father believed his son was 'dull-headed' rather than autistic.

Help-seeking Behavior

At what age are children with autism first taken to a doctor or specialist, and what kind of help is sought? Cohen and Volkmar poignantly note, 'where there is no cure, there are a hundred treatments' (1997, p. 950). This statement has particular relevance for Indians: high help-seeking behavior has been noted in South Asians (Dhillon & Srivastava, 1986; Peshwaria et al., 1995), and because autism can easily be perceived as a variety of different problems depending upon which aspect is attended to, the experience of parents of autistic children affords a natural opportunity to understand this cultural process. Help-seeking behavior may be further intensified by the existence of multiple systems of medicine, such as the presence of Allopathic, Ayurvedic, homeopathic, and Unani traditions in India. Lastly, the way these different traditions of medicine view a disorder such as autism is itself an important area of research; for example, virtually nothing is known about how a homeopathic or Ayurvedic doctor conceptualizes and treats a complex set of symptoms such as autism from the perspective of the physician.

The Process of Diagnosis

Criteria used to differentiate autism from other disorders, whether or not a child receives a diagnosis at all, what information is told to parents and what interventions or referrals are made are all critical components of the diagnostic process. Despite the assertion that autism has universally

recognized diagnostic criteria, the degree to which researchers and clinicians follow these criteria may vary widely across cultures. The actual use of diagnostic systems such as the DSM and ICD 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. If, for example, a professional does not regard delays in language as atypical until a late age, 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 result of numerous factors, including interpretation of symptoms and the perceived relevance of criteria (Fryers, 1986). Research on diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians found that, 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 (Daley & Sigman, 2002).

Treatment

In non-Western countries, what options for treatment are available, are they specific to the problem, what alternative practices are used, are any treatments effective, and does treatment occur at all? As noted above, there is a proliferation of treatment options in the US, but the study of autism in other cultures may expose researchers to treatments not used in the West, as well as misuse of those that are. The pharmaceutical industry in India has been well described (e.g. Nunley, 1996; Richter, 1996), and children in the India study had been prescribed over 50 different medications for their 'autism.' Although there is no pharmacological cure for the disorder and only a few medications that appear to be effective in relieving symptoms, 75% of the sample had taken medication in the past, and 42% were taking medication at the time of the interview. Parents in the India study also reported using megavitamin therapy in the form of a U.S. product called *SuperNu Thera*, with little report of success. Other treatments used by Indian families included pranic healing, reflexology, astrologists, acupressure, speech therapy, vitamin therapy, tutoring, Siddha, behavior therapy, and yoga, and over half the sample had used either or both Ayurvedic and homeopathic treatment.

Family Functioning

Areas such as the perceived burden and distribution of care for the child with a disability, the forms of social support that are available and used,

and the ways in which a disabled child impacts other members of the family are all part of the experience of an autistic family member. The presence of a child with autism may make family roles and interconnectedness more salient. For example, a number of Indian families chose to have another child after their child with autism for the explicit purpose of having someone to care for the child with autism after the parents' death, and sibling caretaking was common. One mother expressed chagrin at the movement to recognize autism as a genetic disorder – she feared that the families of prospective son-in-laws of her non-autistic daughter would be wary of bringing a genetic condition into their family.

Community and Legal Issues

Awareness and attitudes among the general population and legislation designed to enhance the lives of people with autism clearly vary cross-culturally. Reiter (1999) has emphasized the importance of research questions such as whether similar issues occur across cultures in providing services and policies for people with disabilities and what different approaches are taken in providing services. In India, legal recognition of autism as a disorder only occurred in 1999. Before that, schools for children with autism were not eligible for government funding, nor were families eligible for concessions that people with other disabilities could receive. Community and cultural beliefs relate directly to legislation to protect and enhance the lives of people with autism and their families, and also impact the daily lives of families, as observed in India. One mother in the study reported going to the police station when her autistic son was lost. She tearfully related to the researcher that she had used the word '*pahgal*' ('crazy') to convey meaning to the officer. This example clearly highlights the interaction between public awareness and personal suffering.

Socialization

This domain includes how parental values are instilled in children and which aspects of culture are selected for transmission to children with disabilities. In a culture in which social participation is the basis of personhood, what happens to the socialization process for a child with a disability, particularly a disability that, by definition, is a deficit in social relatedness? The rich area of childhood socialization cross-culturally becomes even more fascinating when the process includes the question of socialization of children who may be 'outside' culture in many respects.

These seven domains are among many that are possible to explore using autism as a vehicle. They have clear relevance whether or not the biological condition of autism actually varies from one culture to the next, given that

social and cultural influences clearly shape a disorder. Still, if major differences in expression of the disorder *are* found from one culture to another, the result would be an even more explicit opportunity to use culture to better understand autism.

One direction of research would be to investigate which aspects of the disorder differ, and how these differences relate to linguistic differences, socialization goals and practices, and other culturally mediated processes. For example, a common trait associated with language in autism is the tendency for a child to reverse pronouns. If a language does not contain pronouns, are there other identifiable idiosyncrasies of communication? Given that autism is often thought of as a disorder of communication, how does multilingualism shape the communication aspects of the disorder? In the India sample, bilingualism among verbal autistic children was commonplace. One teenage participant was fluent in five languages: she heard and expressed herself the most in Bengali, followed by Malayam, then English, Hindi and Tamil, and was able to write in Bengali, English and Hindi with correct grammar. This teen automatically spoke the language of the person she was encountering, which suggests how bilingualism might be used as part of a theory of mind paradigm.³

Another example of this line of research: one of the hallmarks of autism is aloofness or aloneness, and oftentimes a lack of social reciprocity. In a culture in which childhood sociability is less emphasized, does such aloofness not appear as central a symptom? Yet another interesting issue is the extent to which differences in symptoms can be linked to treatment, or the absence of treatment. In the US, we do not have a current perspective of what the untreated course of autism looks like, because most children in the US attend school at the very minimum. Yet it is wholly possible that many children with autism in developing countries receive literally no intervention beyond family care, thus providing a natural experiment.

Research could also examine prevalence across cultures. Estimates of the prevalence of autism generally range from 3.3 to 16 per 10,000 (Wing, 1993), although other estimates are as high as 91 per 10,000 (Wolff, 1995). Several researchers have noted an increased number of children diagnosed as autistic in recent years, but have not determined if the increase is real or a result of changes in criteria and increased awareness (Gillberg & Wing, 1999; Webb, Lobo, Herras, Scourfield, & Fraser, 1997; Wing, 1996). Given the difficulty of making comparisons of prevalence across cultures without consensus of diagnostic criteria and definitions (Canino, 1996), undertaking a serious epidemiological study in a non-Western county would be a valuable contribution to the field.

A third, and perhaps most compelling reason to conduct such research stems from the notion that the treatment needs of children and families may differ substantially from one country to another (Fryers, 1986).

Regardless of the similarity or dissimilarity in symptoms across cultures, the practice in the West has been to recommend treatment based on the individual characteristics of the child. In other words, there is no automatic course of treatment that is prescribed for children in the US, and similarly, at the national level, it is not acceptable to assume that any one intervention will be superior or more appropriate than another. The notion that treatment methods can simply be developed in the West and 'exported' elsewhere is perhaps as flawed as the more general notion of the applicability of Western psychology in the context of a non-Western country. Although the World Health Organization (WHO) has commented considerably less on the disorder of autism than on mental retardation and physical impairment, the WHO report on evaluation of methods for treatment of mental disorders notes the importance that treatment methods for autism be 'relevant to the setting in which they are deployed . . . because of the extent to which disorders and treatments are influenced by cultural, developmental, and environmental factors' (WHO, 1991, p. 65). Given this issue, part of the rationale to research autism in non-Western contexts surely must be to help develop and promote methods of rehabilitation and training that are consistent with local cultural practices and beliefs.

Conclusion

If any condition can be categorized as culturally invariant, autism appears to be a good candidate given its biological underpinnings. However, the existing literature of case reports and limited ethnographic study, suggests that the most accurate view of autism is as a biological condition that is culturally shaped in symptoms and course.

Research on the developmental disorders within a cultural context and in non-Western countries has received limited attention from both the fields of autism and medical anthropology. Notable efforts include case studies, brief reviews, and several forays into cross-cultural comparison, however, few studies have undertaken a serious discussion of cultural factors. This lack that may reflect beliefs that the disorder is either rare or that it is completely invariant across cultures and hence, not a critical area of study. Regardless of past oversights, autism organizations around the world are likely to continue to grow and draw attention to the need for culturally informed research.

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Notes

1. A list of addresses for international organizations is available at: <http://www.autism-india.org>
2. For example, one area of research has focused on parental issues, with research in Bangladesh (Zaman & Yasmeen, 1990) examining parental personality traits, a study on parental stress and coping in the Philippines (Liwag, 1989), two reports on parent training in Turkey (Akkok, 1994; Kuloglu-Aksaz, 1994), and a study on coping strategies of mothers in Poland (Pisula, 1996). These studies exist largely in isolation, with little connection to the wider body of research on either autism or cultural aspects of parenting. Lotter (1978) provided an overview of autism in several African countries, and separate reports have been published about children in Nigeria (Akande, 1998), South Africa (Molteno, Molteno, Finchilescu, & Dawes, 2001; Szabo & Aber, 1992), and Kenya (Dhadphale, Lukwago, & Gajjir, 1982). Although the following is not a comprehensive list, studies are also available from Kuwait (al Saad, 2000; Fields, 1996), Israel (e.g. Barak, Kimhi, Stein, Gutman, & Weisman, 1999; Barak, Ring, Sulkes, & Gabbay, 1995), Peru (Bondy & Frost, 1993; Gomberoff, Noemi, & de Gomberoff, 1991), Argentina (Cecchi, 1990), Chile (Donovan & Olivari, 1989), Japan (e.g. Kurita, Miyake, & Katsuno, 1989; Kobayashi & Murata, 1992), Mexico (e.g. Marcin, 1991; de Pla, 1991), Brazil (Pinto, 1982), Columbia (Villareal & Gaviria, 1987), Sri Lanka (De Silva, 1988), Korea (Lee & Kobayashi, 1996), Singapore (Chen & Bernard-Opitz, 1993), Taiwan (Chen & Hsiao, 1989), China (e.g. Kuo-Tai, 1992; Lam & Rao, 1993), Hong Kong (e.g. Carmody, Kaplan, & Gaydos, 2001; Chung, Luk, & Lee, 1990), Malaysia (Takeuchi, Kubota, & Yamamoto, 2002), and several countries of Eastern Europe, including Poland (Koscielska & Nowak, 1988), Romania (Faur, 1981), Romanian orphans (Rutter, Kreppner, & O'Connor, 2001; Rutter et al., 1999) Bosnia (Bujas-Petkovic, 1993), Yugoslavia (Milic-Rasic, Vranjesevic, Jovic, & Pantovic, 1996) the Czech Republic (Propper, Hrdlicka, Lisy, & Belsan, 2001; Simonova, 1996) and the Soviet Union (Lebedinskaya & Nikolskaya, 1993) among others.
3. 'Theory of mind' refers to the ability to take the perspective and point of view of others and was originally tested in a paradigm developed by Wimmer and Perner (1983). An extensive body of literature has examined theory of mind in children with autism; see Marris (1999) and Baron-Cohen (2001) for recent reviews of this work.

References

- Akande, A. (1998). Self-monitoring of autistic behavior. *Psychology: A Journal of Human Behavior*, 35, 23–29.
- Akkok, F. (1994). An overview of parent training and counselling with the parents

- of children with mental disabilities and autism in Turkey. *International Journal for the Advancement of Counselling*, 17, 129–138.
- al Saad, S. (2000). Implementation of an educational program for children with autism: The case of Kuwait. *International Journal of Mental Health*, 29, 32–43.
- Asuni, T. (1988). Sociocultural and economic determinants of rehabilitation. *International Journal of Mental Health*, 17, 8–14.
- Barak, Y., Kimhi, R., Stein, D., Gutman, J., & Weisman, A. (1999). Autistic subjects with comorbid epilepsy: A possible association with viral infections. *Child Psychiatry & Human Development*, 29, 245–251.
- Barak, Y., Ring, A., Sulkes, J., & Gabbay, U. (1995). Season of birth and autistic disorder in Israel. *American Journal of Psychiatry*, 152, 798–800.
- Baron-Cohen, S. (2001). Theory of mind and autism: A review. In L. M. Glidden (Ed.), *International review of research in mental retardation: Autism* (Vol. 23, pp. 169–184). San Diego: Academic Press.
- Berry, J. W., Poortinga, Y. H., Segall, H. H., & Dasen, P. R. (1992). *Cross cultural psychology: Research and applications*. Cambridge: Cambridge University Press.
- Bettleheim, B. (1967). *The empty fortress*. New York: Free Press.
- Bilu, Y., & Goodman, Y. C. (1997). What does the soul say? Metaphysical uses of facilitated communication in the Jewish ultraorthodox community. *Ethos*, 25, 375–407.
- Bondy, A. S., & Frost, L. A. (1993). Mands across the water: A report on the application of the Picture-Exchange Communication System in Peru. *Behavior Analyst*, 16, 123–128.
- Bujas-Petkovic, Z. (1993). The three-dimensional modeling ability of a boy with autism. *Journal of Autism & Developmental Disorders*, 23, 569–571.
- Campbell, M. (1996). Nosological comments on culture and childhood-onset disorders. In J. E. Mezzich, A. Kleinman, H. Fabrega, & D. Parron (Eds.), *Culture and psychiatric diagnosis: A DSM-IV perspective* (pp. 283–285). Washington, DC: American Psychiatric Press.
- Canino, G. (1996). Cultural comments on childhood-onset disorders: II. In J. E. Mezzich, A. Kleinman, H. Fabrega, & D. Parron (Eds.), *Culture and psychiatric diagnosis: A DSM-IV perspective* (pp. 279–281). Washington, DC: American Psychiatric Press.
- Carmody, D. P., Kaplan, M., & Gaydos, A. M. (2001). Spatial orientation adjustments in children with autism in Hong Kong. *Child Psychiatry and Human Development*, 31, 233–247.
- Cecchi, V. (1990). Analysis of a little girl with an autistic syndrome. *International Journal of Psycho-Analysis*, 71, 403–410.
- Chen, C. H., & Hsiao, K. J. (1989). A Chinese classic phenylketunuria manifested as autism. *British Journal of Psychiatry*, 155, 251–253.
- Chen, S. A., & Bernard-Opitz, V. (1993). Comparison of personal and computer-assisted instruction for children with autism. *Mental Retardation*, 31, 368–376.
- Chung, S. Y., Luk, S. L., & Lee, P. W. H. (1990). A follow-up study of infantile autism in Hong Kong. *Journal of Autism and Developmental Disorders*, 20, 221–232.
- Cohen, D. J., & Volkmar, F. (1997). Conceptualizations of autism and intervention

- practices: International perspectives. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 947–950). New York: Wiley.
- Collaborative Linkage Study of Autism (CLSA). (1999). An autosomal genome screen for autism. *American Journal of Medical Genetics (Neuropsychiatric Genetics)*, 88, 609–615.
- Connors, J. L. (1993). *Navajo perceptions of autism and social competence: A cultural perspective*. University of Wisconsin-Madison, Madison. Unpublished doctoral dissertation. Dissertation Abstracts International. Jan. 53 (7-A): p. 2431.
- Cuccaro, M. L., Wright, H. H., Rownd, C. V., Abramson, R. K., Waller, J., & Fender, D. (1996). Brief report: Professional perceptions of children with developmental difficulties: The influence of race and socioeconomic status. *Journal of Autism and Developmental Disorders*, 26, 461–469.
- Daley, T. C. (2001, April). *Explaining autism: Attribution of cause among Indian parents*. Poster session presented at the Biennial meeting of the Society for Research in Child Development, Minneapolis, MN.
- Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32, 13–23.
- de Pla, E. P. (1991). El niño psicótico y la escuela: Un enfoque psicoanalítico. *Psicosis y Retardo Mental*, 3, 1–47.
- De Silva, D. G. H. (1988). Rett syndrome in Sri Lanka. *Ceylon Medical Journal*, 33, 73–75.
- Desjarlais, R., Eisenberg, L., Good, B., & Kleinman, A. (1995). *World mental health: Problems and priorities in low-income countries*. New York: Oxford.
- Dhadphale, M., Lukwago, M. G., & Gajjir, M. (1982). Infantile autism in Kenya. *Indian Journal of Pediatrics*, 49, 145–148.
- Dhillon, H. S., & Srivastava, V. P. (1986). How people perceive illness and what they do when they fall sick. In A. B. Hiramani & N. Sharma (Eds.), *Research in health practices* (pp. 287–300). New Delhi: Central Health Education Bureau.
- Donovan, L., & Olivari, C. (1989). Autismo infantil: Un proceso co-terapéutico a dos voces. *Revista Terapia Psicológica*, 8, 44–49.
- Egdell, H. G., & Nikapota, A. D. (1991) Mental health problems. In P. Stanfield, M. Brueton, M. Chan, M. Parkin, & T. Waterson, (Eds.), *Diseases of children in the subtropics and tropics* (pp. 398–419). London: ELBS.
- Ellenberger, H. F. (1968). Psychiatric impressions from a trip to Dakar. *Canadian Psychiatric Association Journal*, 13, 539–545.
- Faur, S. (1981). The possibilities and limits of recuperation in verbal communication of the autistic infant. *Neurologie, Psihiatrie, Neurochirurgie*, 26, 225–227.
- Fields, J. I. (1996). Aetiologies of autism: Psychodynamic, pharmacological and behavioural, related to Kuwait. *Early Child Development & Care*, 125, 27–51.
- Fryers, T. (1986). Screening for developmental disabilities in developing countries: Problems and perspectives. In K. Marfo, S. Walker, & B. Charles (Eds.), *Childhood disability in developing countries* (pp. 27–40). New York: Praeger.

- Gillberg, C., Schaumann, H., & Gillberg, I.C. (1995). Autism in immigrants: Children born in Sweden to mothers born in Uganda. *Journal of Intellectual Disability Research*, *39*, 141–144.
- Gillberg, C., Steffenburg, S., & Schaumann, H. (1991). Is autism more common now than ten years ago? *British Journal of Psychiatry*, *158*, 403–409.
- Gillberg, C., & Wing, L. (1999). Autism: Not an extremely rare disorder. *Acta Psychiatrica Scandinavica*, *6*, 399–406.
- Gomberoff, M., Noemi, C., & de Gomberoff, L. P. (1991). Detección del objeto autista en el análisis de una niña psicótica. *Transiciones*, *2*, 36–52.
- Hackett, R., & Hackett, L. (1999). Child psychiatry across cultures. *International Review of Psychiatry*, *11*, 225–235.
- Haznedar, M. M., Buchsbaum, M. S., Wei, T., Hof, P. R., Cartwright, C., Bienstock, C. A., & Hollander, E. (2000). Limbic circuitry in patients with autism spectrum disorders studied with positron emission tomography and magnetic resonance imaging. *American Journal of Psychiatry*, *157*, 1994–2001.
- Ingstad, B., & Whyte, S. R. (Eds.). (1995) *Disability and culture*. Berkeley: University of California Press.
- Kleinman, A. (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.
- Kobayashi, R., & Murata, T. (1992). Factors determining the capacity of autistic adults to become independent and self-supporting. In C. Chiland & J. G. Young (Eds.), *New approaches to mental health from birth to adolescence* (pp. 252–263). New Haven, CT: Yale University Press.
- Koscielska, M., & Nowak, M. (1988). Interactions between autistic children: An attempt at measurement in developmental categories. *Polish Psychological Bulletin*, *19*, 155–156.
- Kuloglu-Aksaz, N. (1994). The effect of informational counseling on the stress level of parents of children with autism in Turkey. *Journal of Autism and Developmental Disorders*, *24*, 109–110.
- Kuo-Tai, T. (1992). Infantile autism in China. In C. Chiland & J. G. Young (Eds.), *New approaches to mental health from birth to adolescence* (pp. 375–383). New Haven, CT: Yale University Press.
- Kurita, H., Miyake, Y., & Katsuno, K. (1989). Reliability and validity of the Childhood Autism Rating Scale – Tokyo Version (CARS-TV). *Journal of Autism and Developmental Disorders*, *19*, 389–396.
- Lam, M. K., & Rao, N. (1993). Developing a Chinese version of the Psychoeducational Profile (CPEP) to assess autistic children in Hong Kong. *Journal of Autism and Developmental Disorders*, *23*, 273–279.
- Lane, H., & Pillard, R. (1978). *The wild boy of Burundi: A study of an outcast child*. New York: Random House.
- Lee, H., & Kobayashi, S. (1996). The process of initial language development in children with autism. *Japanese Journal of Special Education*, *34*, 33–34.
- Lebedinskaya, K. S. & Nikolskaya, O. S. (1993). Brief report: Analysis of autism and its treatment in modern Russian defectology. *Journal of Autism and Developmental Disorders*, *23*, 675–679.
- Leonard, C. J. (1985). Brief outlines of the parent/family reaction to childhood

- disability in families from 3 ethnic minority groups. *International Journal for the Advancement of Counselling*, 8, 197–205.
- Liwag, E. C. D. (1989). Mothers and fathers of autistic children: An exploratory study of family stress and coping. *Philippine Journal of Psychology*, 22, 3–16.
- Lord, C., & Risi, S. (2000). Diagnosis of autism spectrum disorders in young children. In A. M. Wetherby & B. M. Prizant (Eds.), *Autism spectrum disorders: A transactional developmental perspective* (pp. 11–30). Baltimore: Brookes.
- Lotter, V. (1978). Childhood autism in Africa. *Journal of Child Psychology and Psychiatry*, 19, 231–244.
- Lotter, V. (1980). Methodological problems in cross-cultural epidemiological research: Illustrations from a survey of childhood autism in Africa. In F. Earls (Ed.), *Studies of children* (pp. 126–144). New York: Prodist.
- Marcin, C. (1991). Modelos de intervención terapéutica en el autismo. *Asociación Mexicana del Estudio del Retraso Mental y la Psicosis Infantil*, 3, 65–85.
- Marfo, K., Walker, S., & Charles, B. (Eds.). (1986). *Childhood disability in developing countries*. New York: Praeger.
- Marris, C. (1999). Autism: A critical review of psychological theories with particular reference to the development of social understanding. *Early Child Development & Care*, 153, 65–101.
- Milic-Rasic, V., Vranjesevic, D., Jovic, N., and Pantovic, S. (1996). Autism and the complex of tuberous sclerosis: A case report. *Psihijatrija Danas*, 28, 473–481.
- Molteno, G., Molteno, C. D., Finchilescu, G., & Dawes, A. R. L. (2001). Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research*, 45, 515–520.
- Moreno, C. L. (1996). *Understanding 'El autismo': A qualitative study of the parental interpretation of autism*. The Ohio State University, Mar. 56. p. 3745.
- Morgan, H. (1996). *Adults with autism: A guide to theory and practice*. Cambridge: Cambridge University Press.
- Nunley, M. (1996). Why psychiatrists in India prescribe so many drugs. *Culture, Medicine and Psychiatry*, 20, 165–197.
- Peshwaria, R., Menon, D. K., Ganguly, R., Roy, Pillay, R. P. R. S., & Gupta, A. (1995). *Understanding Indian families having persons with mental retardation*. Secunderabad: National Institute for the Mentally Handicapped.
- Pinto, P. (1982). O autismo infantil. Análise de uma hipótese etiopatogénica: Considerações sobre a neurobiologia da senso-percepção. *Journal Brasileiro de Psiquiatria*, 31, 79–85.
- Pisula, E. (1996). Coping strategies and psychological well-being in mothers of children with disabilities. *Psychiatria Polska*, 30, 221–232.
- Probst, P. (1998). Child health-related cognitions of parents with autistic children: A cross-national exploratory study. In U. P. Gielen & A. L. Comunian (Eds.), *The family and family therapy in international perspective* (pp. 461–483). Trieste: Lint.
- Propper, L., Hrdlicka, M., Lisy, J., & Belsan, T. (2001). Structural brain abnormalities in childhood autism. *Ceska a Slovenska Psychiatrie*, 97, 269–275.

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- Reiter, S. (1999). Conclusion: Cross-cultural perspectives – diversity and universalism. In P. Retish & S. Reiter (Eds.), *Adults with disabilities: International perspectives in the community* (pp. 325–335). Mahwah, NJ: Erlbaum.
- Retish, P., & Reiter, S., (1999). *Adults with disabilities: International perspectives in the community*. Mahwah, NJ: Erlbaum.
- Richter, M. (1996). Popular perceptions of medicine: A South Indian case study. In M. Nichter & M. Nichter (Eds.), *Anthropology and international health: Asian case studies* (pp. 203–237). Dordrecht: Gordon & Breach.
- Ritvo, E. R., Cantwell, D., Johnson, E., Clements, M., Benbrook, F., Slagle, S., Kelly, P., & Ritz, M. (1971). Social class factors in autism. *Journal of Autism and Childhood Schizophrenia*, 1, 297–310.
- Rutter, M., Andersen-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., Kreppner, J., Keaveney, L., Lord, C., & O'Connor, T. G. (1999). Quasi-autistic patterns following severe early global privation. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 40, 537–549.
- Rutter, M. L., Kreppner, J. M., & O'Connor, T. G. (2001). Specificity and heterogeneity in children's responses to profound institutional privation. *British Journal of Psychiatry*, 179, 97–103.
- Sanua, V. D. (1984). Is infantile autism a universal phenomenon? An open question. *International Journal of Social Psychiatry*, 30, 163–177.
- Seu, G. H. (1992). *Cross-cultural study of autism in South Korea and the United States*. University of Texas, Austin. Dissertation Abstracts International, March 52 (9-A).
- Shaked, M. (2001). *Cultural construction of disorder: Autism in ultra-orthodox society in Israel*. The Hebrew University, Israel. Dissertation Abstracts International.
- Shu, K. E. (1989). *Professional perceptions of the differences in parental attitudes and behaviors and the behavioral manifestations of autism in Chinese and Caucasian children*. Columbia University Teachers College. Dissertation Abstracts International, September (A 50/03).
- Simonova, H. (1996). Autism: Behavioral features. *Homeostasis in Health & Disease*, 37, 143–144.
- Smadi, J. M. (1986). *A validation study of the Jordanian version of the Autism Behavior Checklist (ABC) of the Autism Screening Instrument for Educational Planning (ASIEP)*. Michigan State University. Dissertation Abstracts International, March 46 (9-A).
- Steffenburg, S., & Gillberg, C. (1986). Autism and autistic-like conditions in Swedish rural and urban areas: A population study. *British Journal of Psychiatry*, 149, 81–87.
- Szabo, C. P., & Aber, D. (1992). Asperger's syndrome: A valid DSM IV diagnostic entity? A case report. *Southern African Journal of Child & Adolescent Psychiatry*, 4, 3–7.
- Tager-Flusberg, H., Joseph, R., & Folstein, S. (2001). Current direction in research on autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 21–29.
- Takeuchi, K., Kubota, H., & Yamamoto, J. (2002). Intensive supervision for families

- conducting home-based behavioral treatment for children with autism in Malaysia. *Japanese Journal of Special Education*, 39, 155–164
- Tungaraza, F. D. (1994). The development and history of special education in Tanzania. *International Journal of Disability, Development and Education*, 41, 213–222.
- Varma, V. K., & Chakrabarti, S. (1995). Social correlates and cultural dynamics of mental illness in traditional society: India. In I. Al-Issa, (Ed.), *Handbook of culture and mental illness: An international perspective*. Madison, WI: International Universities Press.
- Villareal, L., & Gaviria, P. (1987). Características del aprendizaje en los niños autistas: Sus implicaciones para las estrategias de tratamiento. *Enuentro Nacional de Educación Especial*, 35–63.
- Webb, E. V. J., Lobo, S., Herras, A., Scourfield, J., & Fraser, W. I. (1997). The changing prevalence of autistic disorder in a Welsh health district. *Developmental Medicine and Child Neurology*, 39, 150–152.
- Westermeyer, J. (1979). Folk concepts of mental disorder among the Lao: Continuities with similar concepts in other cultures and in psychiatry. *Culture, Medicine & Psychiatry*, 3, 301–317.
- Whyte, S. R., & Ingstad, B. (1995). Disability and culture: An overview. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture* (pp. 3–32). Berkeley: University of California Press.
- Wimmer, H., & Perner, J. (1983). Beliefs about beliefs: Representation and constraining function of wrong beliefs in young children's understanding of deception. *Cognition*, 13, 103–128.
- Wing, L. (1993). The definition and prevalence of autism: A review. *European Child and Adolescent Psychiatry*, 2, 61–74.
- Wing, L. (1996). Autism spectrum disorders: No evidence for or against an increase in prevalence. *British Medical Journal*, 312, 327–328.
- Wolff, S. (1995). *Loners: The life path of unusual children*. London: Routledge.
- World Health Organization. (1991). *Evaluation of methods for the treatment of mental disorders: WHO technical report series, 812*. Geneva: World Health Organization.
- Zaman, S. S., & Yasmeen. (1990). Personality traits of parents of autistic children. In S. S. Zaman (Ed.), *Research on mental retardation in Bangladesh* (pp. 162–175). Dhaka: Protibondhu Foundation.

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