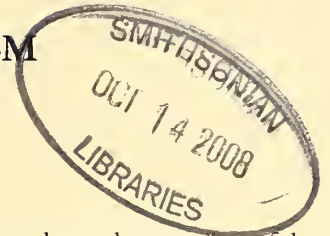


REMAPPING THE WORLD OF AUTISM

by Roy Richard Grinker



As an anthropologist, I have learned that the best way to learn about the rules of any society is to see them broken. That is why sickness, when it prevents people from living up to the rules of social behavior, can teach us so much about culture. When everything goes smoothly and expectations are met, the rules fade into the background of social life and become almost invisible. We learn more when things go wrong, as I found out when I started a research project to study autism across cultures. I wanted to know if autism existed in other cultures, and if so, what people did about it. I traveled to Korea, South Africa, and India, and communicated by telephone and email to mothers and fathers in more than a dozen other countries.

What I discovered in all of these places was that brave and dedicated parents, like the Indian mothers described in this article, wage a constant battle to balance the rules of their society with their own personal beliefs about their children. In every country, it is a mother's eyes that are the first to truly see her child and accept her child's difference. But simply to see a child with autism is not the same thing as helping him or integrating him into a social world. Those doors have to be worked open.

As we will see, a group mothers in India can teach us a great deal about the obstacles to mental health care in India and the rules of Hindu society. These mothers all raised boys with autism, a disorder that always emerges before the age of three, in boys four times more often than in girls, with a constellation of symptoms, sometimes severe and sometimes moderate, that includes impairments in language and social interaction, and restricted interests and activities. Although the symptoms

of autism are the same everywhere, the meaning of those symptoms varies from culture to culture. For these mothers, raising a child with autism in India became an act of resistance against the expectations of their culture. Their stories also help us understand the difference between the concepts of "disease" and "illness." In the view of anthropologist Arthur Kleinman, a disease occurs when something is wrong with our bodily organs or systems, whereas illness is the experience of negative or unwanted changes in our bodies or our ability to function in society. Autism is both a disease and an illness, and it cannot be otherwise.

The experiences of autism—as an illness, not as a disease—even by mothers from the same country can be vastly different. These experiences are shaped by the kind of community each woman lives in, her ancestry, the gender roles that are valued in her culture and how they are played out in her home, her culture's tolerance for diversity and difference, and even her own personality and personal will to care for her child in the face of harsh criticism from the people closest to her. Anthropology can play an important role in understanding how culture affects and will continue to affect the way we view autism, and therefore also, the way we raise our children.

In India, most of the children who would be given the diagnosis of autism if they were in the United States are instead called either mentally retarded (MR) or mad (in Hindi, *paagol*). With either diagnosis, the family must face an extraordinary amount of social stigma. Tamara Daley, an American psychologist who has studied autism in India, believes that many doctors in India actually do know something about autism but are reluc-



tant to give the diagnosis, either because they think there is nothing that can be done to help anyway or because they assume the families they see, many of which are illiterate or poorly educated, will be unable to understand what autism means. Until 1999 the Indian government did not even recognize autism as a disorder.

Consider the case of a teenage boy I met in New Delhi named Rohit. Before he was two, Rohit's parents knew something was wrong. He didn't speak much, showed no interest in social interaction, had rigid, patterned behaviors, and an odd gait. Rohit's parents tried religious healers but when there was no improvement in his behavior, they moved on to medical doctors who diagnosed him with mental retardation.

By the age of 5, Rohit was interested mostly in memorizing license plate numbers and showed great skill in identifying vehicle makes and models. By the age of 8, his speech though still delayed was articulate and fluent, but he had no friends. He still kissed and hugged his mother in public, which is inappropriate in India, and used obscene words when talking to neighbors. Pediatricians said that Rohit needed a more lively social environment. No elementary school would take him, so his parents paid \$60 a month to place him in a good private school for a diverse array of children with special needs, many of whom were blind, deaf, mentally retarded, or had cerebral palsy. Rohit was enrolled under the diagnosis "mental retardation."

Six years later, when Rohit was 14, and just as socially impaired as ever, a British-trained psychiatrist in Delhi came to the school to give a lecture to parents about developmental disorders, including autism, and urged the school to administer an autism rating scale to its students. The idea was to screen potential cases for further diagnostic assessment. Rohit's parents resisted. They had already seen dozens of doctors over the years and each time they were told that Rohit was mentally retarded. They'd already gotten comfortable with the diagnosis.

After the lecture, still knowing little about autism, they told the school director, "Rohit cannot have autism because he looks fine physically." Ten months later, the school prevailed over the parents' objections. Rohit was tested and then diagnosed with autism. Further examination showed no evidence of mental retardation. In fact, his IQ is above average. The psychiatrist promptly prescribed

a small dose of an anti-depressant that helps reduce anxiety and, in people with autism, facilitates assertiveness. Within three months the family reported that Rohit's social relatedness had improved noticeably. It had taken them fifteen years to get proper treatment for Rohit.

There is emerging in India a disjunction between doctors, who often rely on outdated medical literature, and parents, who are increasingly well informed. The parents' source is the internet, a central character in nearly every autism story I've ever heard, anywhere. Many Indian parents have set up Google alerts to send themselves daily notices of every news article published on autism in any newspaper in the world. Through such information, autism is slowly but surely becoming less exotic in India and so also less shameful.

One day, as I talked to a group of three Bengali mothers waiting to pick up their children from the only school for autistic children in New Delhi (pop. 14 million), called Open Door, I noticed a remarkable similarity to some of the positive conversations I had heard in the United States. In the U.S. parents often talk about whether Albert Einstein or Isaac Newton were high functioning autistic people. Newton, for example, spoke little, had few friends, and was extremely awkward socially. In India, such comparisons involve religious figures. One of the Bengali women commented to me, "You know, our god, Siva, was like an autistic person. He couldn't relate to others, he walked around naked." The other women lit up and joined in. "He had no friends!" "Yes, he was totally disconnected from the world." "He was abnormal." Of course, they are right, and this is why Siva's parents-in-law to-be were so outraged that their daughter might marry him.

"I heard that Ramakrishna was autistic too," one woman said, but she could not say why. She was referring to the Bengali saint, Sri Ramakrishna Paramahansa, who was illiterate and bizarre, but revered in India. As a child, he wore girl's clothing and acted like a girl, sometimes pretending that he was a widow or an abandoned wife, and he worshipped the Lord Krishna through *madhurya bhava*, a woman's deeply spiritual desire for her lover. He was thought to be *paagol* (mad) but also divinely inspired.

There is a long tradition of unusual saints and other holy men and women in India who had special powers but who were incapable of having appropriate social relationships. In this context, it is not that surprising to hear

mothers describe their children with autism as untainted by the evils of civilization and with terms like “pure” and “close to God.” In fact, an important stage of the ideal Hindu life course is the eventual separation from the social world, the renunciation of society, with the greatest value given to the forest dweller who abrogates all social ties and family obligations.

Despite the extraordinary cultural variation of India—where there are close to four hundred different languages in a country roughly one third the size of the United States—Hindu child rearing practices are remarkably consistent. Among all Hindu communities, the mother and child are nearly inseparable for the first two years of life, with mothers holding their children at the hip even when working around the house. Up until the age of two or two and a half, children are kings, sleeping with their mothers, the breast always accessible enough so they never have to cry for long. Weaning usually occurs between the ages of 2 and 3 but in many cases, where there is no younger sibling, a child may breast-feed until the age of 5 or 6.

In general, Hindu boys are tied to their mothers until about the age of 5, when mothers no longer indulge them and they enter the world of the father and his extended family. Some Indian psychoanalysts have suggested that the tie between the child and the mother, especially between the son and mother, is so close that it is almost pathological. A boy is so important to a mother's status in her family and society at large that her emotional attachment to him—or reverence—may be excessive from a western perspective. The father is typically disengaged during early childhood. While the child is enmeshed with his mother, however, the father and the extended family are always nearby. Gently the mother weans the child not only from the breast but from the dependence on her and pushes him or her into the bosom of the extended family: the father and, figuratively speaking, dozens of mothers.

The mother essentially renounces the son around the time he enters primary school. Mothers tease their children by suggesting that they will give them away, discouraging attention-getting behaviors, encouraging self-restraint, and, if they do indulge the child, rejecting them afterwards. For example, a mother might say, “you had your milk, now get out of the house.” Other relatives push him to voluntarily abandon his mother. They guide him to either the extended family, joint family, or both, rather than to inde-

pendence, and promote a familial rather than an individual identity. This structure is changing rapidly, especially in urban India and in the Indian diaspora, where men and women are entering competitive marketplaces that place a high value on individualism. Still, just as Americans idealize the nuclear family at a time when nearly half of all American children live in single parent households, the ideals of the conventional Hindu family persist. For the mothers of children with autism, however, the disorder disrupts any hope of having their children merge with either an extended or joint family.

Throughout the world, autism is commonly considered a disorder that is about being socially disconnected, and this is true in India as well. Still, in India, autism takes a culturally specific form where the child is largely disconnected from his or her extended family and the maternal bonds remain unbroken. Mothers of children with autism don't feel comfortable asking their in-laws to take a greater role in raising them. Such a mother will not trust her child to anyone. The mother of a mute and mentally retarded autistic child knows her child is incapable of leaving her to spend more time with the extended family, even if the extended family is willing. She will not even try a simple gesture of separation, such as asking a child to get permission from his or her grandparents to eat candy or play a game. Common acts that Hindu mothers use to foster separation, such as teasing the child, have no impact when a child cannot comprehend the meaning (for example, handing the child to a distant relative and saying, “You take him! I don't want him anymore! I've cared for him enough!”).

Shubrha and her husband Rajiv lived with their son Gautam in a joint family enclave until Rajiv was relocated to Delhi. “It was a relief in many ways to be away from my in-laws,” Shubrha told me. They never blamed me for causing his mental problems and behaviors, but they did blame me for not doing the right things to help him. They said I was too overprotective, that I kept him home too much, that he didn't have an exciting environment to help him learn how to talk or be social. After a while the constant criticism gets to you and you think to yourself, ‘okay, if you know how to do it, *you* do it, you are *supposed* to do it anyway if you are his grandmother,’ but then nothing ever happens. But that was okay for me because I knew I could take care of him better than anyone.”

When Gautham was almost 11, he started to go to a school for children with mental retardation not far from his home in Delhi. Though he had been toilet trained a year earlier, he now started to soil his pants on the way home from school, sometimes putting his hands into his pants and playing with his feces. Once home, he refused to let anyone wash him, so Shubhrha had to have someone physically restrain him while she cleaned him up. After a few weeks, Shubhrha decided that the only way to extinguish that behavior was to let him sit and stink in his own feces. "It was horrible," she said. "The house smelled so bad, Gautham had rashes on his thighs and buttocks. I had to keep scented candles and incense burning most of the time, but I held out because I knew the only way to stop the behavior was to show no reaction to it. My husband kept saying, 'how much longer can you take it?' I think it took the better part of a year but it worked."

Within a few years, Rajiv and Shubhrha divorced. Shubhrha now felt free to raise Gautam by herself, often in ways that others might find shocking. When Gautham was about 15 years old, he began to show an interest in sex. He became increasingly irritable and violent and sometimes scratched and hit himself. "No one gives you advice about handling these sexual matters," Shubhrha said, "especially in India where people have so many hang-ups about sex." At a conference about special education in Delhi, Shubhrha met a young American graduate student and asked for his thoughts. Gautam, he believed, needed some kind of course in sex education, but since Gautam was nonverbal, he needed to be educated with visual aids like photographs and videos. Such images are illegal in India, but Shubhrha knew she had to break the law. With the graduate student's help, Gautam learned how to manage his urges and his mood improved dramatically.

From the perspective of most parents, what Shubhrha did might seem bizarre, but I found it made perfect sense, and that it was a deeply compassionate act. Parents of autistic children everywhere improvise, they do what works, and they know their children learn *concretely*, through what is real, visible and tangible rather than through abstract discussions, like lectures about the birds and the bees. There is no denying that Shubhrha clearly improved Gautham's emotional health and taught him what is arguably an important life skill. And that is something she can be proud of.

Amla, another Bengali mother living near Delhi, considers that she has become a "Bohemian." By this she means that she is ill-suited to the society in which she lives, and that she dislikes convention, including materialism and her conservative parents-in-law. "My husband Anil became a Bohemian too, which made him an unsuitable husband, or at least a poor provider. A couple of times he came home without a paycheck and a receipt showing he'd donated the whole thing to a shelter or a hospital." When their autistic and only son, Sunil, was twelve, her husband died suddenly of a heart attack. Normally, the eldest son arranges the cremation and lights the fire by putting a flame to the deceased's lips to symbolize the spirit leaving the body.

"It was chaos in the house," she recalls, "people coming into the house, and the body was there—the typical Hindu thing—and Sunil was going crazy. He was unable to comprehend what was going on, why his father was lying dead in our house, and the crying visitors were too much. He stuck his fingers in his ears and screamed and screamed. I was devastated enough, but I couldn't do this to him." So Amla did what few Hindu women are prepared to do. She took Anil to an electric crematorium and lit the cremation fire herself.

These days one can find urban Hindu women arranging funerals and even cremating their husbands—all Hindus cremate, unlike Muslims who bury—but it is still a clear violation of Hindu laws, and in a conservative family it is unforgivable. Traditionally, women are not allowed to step foot in the burning grounds, and this is true among all Hindus, regardless of linguistic or ethnic group. Her side of the family was appalled, and her husband's family vowed never to see her again.

Mamta's village sits at the foothills of the Himalayas, near the old British hill stations in northern India. She comes to Action for Autism wearing jeans, tee-shirt and sandals one day and then a traditional Indian sari the next. She tells me that when her first child, Ohjyu, was eighteen months old, he didn't seem to behave like the other children did. "I took him to a baby show. They have judges, and mothers exhibit the babies. The babies all did little tasks and won prizes. But my baby wouldn't do anything. I had no idea what was wrong and I didn't even know the word autism."

On the way home from the baby show, she remembered having seen an article about developmental delays in an old issue of the Indian magazine, *Outlook*, and dug it out of the trash. The article listed the symptoms of autism, some of which Ohjyu had, like poor eye contact, speech delay, and an inability to respond to his name.

"That killed me. It was so painful and I didn't share it with anyone, not even my husband. I knew he would be unwilling to believe that something was wrong. I didn't tell my own parents."

Eventually, however, Mamta convinced her husband to take Ohjyu to a pediatrician. The doctor said that Ohjyu's speech was delayed because they lived in an isolated home in the mountains. He recommended taking him into a more stimulating environment, which she and her husband arranged by moving to the city of Gwalior. Although she contemplated terminating her second pregnancy for fear of having another disabled child, her husband refused to even consider it. In Gwalior, little changed for the better with Ohjyu; in fact, he looked worse. So they moved back to Nainital.

Unable to watch the progressive deterioration of her son and against the advice of her husband, and the outrage of her parents-in-law, she devised a plan. She was going to learn how to interact with him and help him learn, even if it meant abandoning her husband and parents-in-law in their mountain village for months, an action many of her friends and neighbors thought was outrageous. Mamta could only imagine the insults hurled behind her back. She took the wide-eyed Ohjyu, along with his infant sister, on the 7 hour train ride to New Delhi. There, a child psychologist diagnosed Ohjyu, then four years old, with autism. Armed with this diagnosis she decided that she was going to reach Ohjyu.

"I belong to a people called the Kumaon, and we don't have many medical experts. I knew something was wrong, but, convincing my people? I cried nights. I was irritable, depressed. My husband avoided me and spent more time working. But now it's out. I spend most of my time with my mother-in-law, and we don't fight much. I respect her power. But I did disobey her. She didn't want me to go to Delhi or see the psychologist. Now when I see these other mothers here in Delhi, I say, 'you have to do what you have to do.'"

Mamta's mother-in-law resisted attempts to understand Ohjyu's developmental problems because she believed it was her husband's family's responsibility. So, on their behalf and leaving Mamta at home, she traveled into the hills to see holy men and tantrics, some of whom said that Ohjyu was possessed by a demon. She eventually reached a conclusion and told Mamta: her husband's family had failed to please the god of the subcaste.

It is hard to exaggerate the importance of boys in Hindu families. Sons carry on the family line and carry out the rituals that are crucial to success in this and subsequent worlds. So in Mamta's community when a girl is born, goats must be sacrificed to please the unhappy village god; only then will they make it possible for boys to be born and be born healthy. When Ohjyu was born, it had been thirteen years since Mamta's parents-in-law had made the last sacrifice. "They wanted to do the sacrifice earlier," Mamta says, "but something kept happening to prevent it. They'd get ready to kill the goats, and then someone would be born. But you can't do the sacrifice at that time without causing big problems. Then someone would die and you can't do the sacrifice then either." So Mamta's parents-in-law now promised to sacrifice fourteen goats, at a cost of about 1,500 rupees (about \$35, U.S.) per goat, to the *devi*, or god, a form of Lord Shiva named Khandenagh. The god is represented by a small pile of stones in a temple in the mountains, where it is tended by priests who perform a small worship ceremony for the *devi* twice a day.

So when I asked Mamta if her parents-in-law blamed *her* for Ohjyu's condition, she seemed perplexed. "They blame themselves for not making the sacrifices. But they do blame me for learning about autism, for leaving them, and for listening to the autism center instead of the priests."

Shubra, Amla, Mamta and the other women I met in India were not going to let stigma, or tradition, or even law get in the way of helping their children. The disturbances they had to deal with were collective because they felt the pressures of Hindu custom. But even if there were no social stigma, they would still be left with personal and emotional turmoil. That is because diseases, however much we see them as biological or material in nature, are total life-changing experiences for parents, families, and communities. The writer, Susan Sontag, once argued that we'd all be better off if diseases were seen only as biological events. She protested the punitive uses of diseases as

metaphors—the way tuberculosis was once the figure of death, or the way people talk about the evils of society as cancers. She argued that if we could rid ourselves of any non-material discussion of illness, there would be less stigma and more social support for the ill, not only those suffering from the most stigmatizing diseases such as AIDS and leprosy, but also for people with more invisible afflictions such as mental illnesses. But if we see a cancer, for example, simply as a tumor, we might easily ignore the com-

plexity of human experience. If we see autism as just a brain disorder, we might miss the little victories that people experience each day as they cope with this illness, not only in the United States, but in New Delhi, and the hills of northern India.

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