Autism without borders

Unstrange Minds: Remapping the World of Autism
Roy R Grinker
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“How dare anyone question the existence of an ‘autism epidemic’?” the mother of an autistic child demanded after reading “Three Reasons not to Believe in an Autism Epidemic,” an article that my co-authors and I—two of us parents of an autistic child and the third autistic herself—wrote to dispel public misconceptions about the recent increase in autism diagnoses.

Such debunking is also the goal of the first half of Unstrange Minds: Remapping the World of Autism. Grinker, an anthropologist, begins by escorting readers back through the first century of American psychiatry. Middle-aged readers are reminded that during our childhood, 1 in every 300 Americans was locked away in a mental institution, a situation that is reflected in the American Psychiatric Association’s previous moniker, the Association of Medical Superintendents of American Institutions. Disabled children were routinely sent to residential institutions. Even pediatric speech therapy and academic tutoring were shame-laden.

Drawing from scientific research, Grinker deftly informs readers how the diagnostic criteria for autism were intentionally broadened. For example, to qualify for diagnosis 20 years ago, an individual needed to be characterized by “a pervasive lack of responsiveness to other people.” More recent criteria require merely “a lack of spontaneous seeking to share achievements with other people,” or peer relationships “less sophisticated” than an individual’s developmental level would predict. Previous diagnostic criteria required “gross deficits in language development,” but more recent criteria require only difficulty in “sustaining a conversation.”

Furthermore, Grinker convincingly argues that rates of epidemiological incidence should not be confused with rates of educational services and other accommodations. The latter are driven by marketplace factors: as diagnostic criteria broaden, more individuals become eligible for services, and as more services become available, more individuals seek diagnoses.

The take-home message from the first half of Grinker’s monograph is credible: given the increasingly broadened criteria and increasingly available services, as well as more rigorous case-finding and the expanding awareness that autistic individuals can possess every level of measured intelligence, the increasing rate of autism diagnoses is expected. Epidemics, however, are defined as dramatically unexpected increases.

After deconstructing the ‘perfect storm’ of the faux autism epidemic, Grinker celebrates contemporary diagnostic rates as “a sign that we are finally seeing and appreciating a kind of human difference that we once turned away from and that many other cultures still hide away in homes or institutions or denigrate as bizarre.” Grinker pinpoints cultures that still lack a name for autism, but warns that assuming autistic people don’t exist in those cultures is as foolhardy as claiming that autistic people didn’t exist prior to Western psychiatry’s coinage of the diagnostic label.

In the second half of this oddly conjoined monographic duplex, Grinker chronicles his life with his own autistic daughter, Isabel. Her passion for Monet’s Garden, her gift of absolute pitch and her prodigious visual-spatial aptitude evoke wonder. But, disappointingly, the majority of the memoir settles for formulaically serving up the components found in other parents’ accounts of their autistic children: when did the parents notice their children developing atypically? Why did they secure the diagnosis? Where did they obtain services, and how do they cope with challenges? Grinker interweaves parental memoirs from India, South Korea, South Africa and other cultures, but these, too, paint by number.

Moreover, Grinker resists drawing the most compelling cross-cultural parallel. Compare the US mother who blames the “Centers for Disease Control’s poisonous schedule of vaccines” for making her child autistic and the US presidential candidate who blames “thousands of chemicals in everything from carpets to clothes” with the Hindus who blame demons, the Navajos who blame disharmonious spirits and the Pygmies who blame ancestral curses. It is a Zulu mother, rather than Grinker, who connects the universal dots: some parents get stuck in angry blame and scapegoating and can’t move forward to acceptance and accommodation.

Indeed, as Grinker toggles between profiling non-Western individuals and profiling his own daughter, he deftly dissect cultural constructions reified by non-Western cultures, but seems oblivious to those reified by his own. For example, is the Western assertion that autistic people are ‘mind blind’ any less a cultural construction than the non-Western assertion that they are spiritually bereft?

Similarly, Grinker naively embraces Western psychiatry’s dogma that the earlier a child is diagnosed, the better, despite the creed’s lack of empirical evidence beyond retrospective chart reviews, which are plagued by hindsight and selection bias. And, quite curiously, Grinker simultaneously embraces John Bruer’s Myth of the First Three Years thesis, which is chock-full of empirical evidence against the presumption that the early years hold open a critical door to development that later years slam shut.

Not unsurprisingly, Grinker’s ability to peel off cultural bias is weakest when he looks at culture-bound beliefs not across the ocean but inside his own home. For instance, Grinker’s strong desire to place his daughter Isabel in a ‘mainstream’ classroom, so that she can be spared disabled peers, smacks of able-ism. Most disconcerting are Grinker’s recurring comparisons between Isabel and her younger sister, Olivia. For example, Olivia is described as socially and intellectually more advanced than Isabel because Olivia engages handily in gossip and enjoys extensively discussing fashion, makeup and television dramas.

Unstrange Minds: Remapping the World of Autism is strongest when it remembers that abnormal is defined only in relation to normal, and the definition of normal, like beauty, often lies in the eyes of the beholder.