

Deep inside the autism enigma

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APRIL 7, 2007

Unstrange Minds:

Remapping the World of Autism

By Roy Richard Grinker

Basic Books, 340 pages, \$32.50

Strange Son: Two Mothers,

Two Sons, and the Quest to Unlock

the Hidden World of Autism

By Portia Iversen

Riverhead, 391 pages, \$31

Although autism was first defined and described in 1934, it took 40 years for it to be officially recognized by the American Psychiatric Association as a disorder other than childhood psychosis. In France, as recently as 2004, autism was seen as a form of schizophrenia rather than a developmental disorder. Today in South Korea, children with autism are frequently diagnosed with a condition called Reactive Attachment Disorder -- often associated with child neglect -- while among the Efe pygmies in Central Africa, a child who begins exhibiting autistic behaviour is understood to be under attack by the family's ancestors and is sent to another village far away where he will not have contact with blood relatives.

These are some of the startling facts gleaned from *Unstrange Minds: Remapping the World of Autism*, by Roy Richard Grinker, professor of anthropology and director of the George Washington Institute of Ethnographic Research. Grinker's interest in the disorder is professional as well as personal. His daughter Isabel was diagnosed in 1994, and his warmth and compassion for autistic children and parents alike shines through this immensely readable and informative narrative that looks closely at how culture influences the ways we understand, classify and treat autistic-spectrum disorders.

Unstrange Minds is a book of two parts. The first looks carefully at autism statistics.

In the 1930s and 1940s, autism was considered a rare condition affecting three in 10,000 children. In 2007, the figure of one in 150 children is now being reported.

Stories in the media are calling the increased number an epidemic, but Grinker argues that the reported figures are not a reflection of an increase in autism, but rather a result of changes in how we perceive psychiatric disorders. He writes, "Under the rubric of autism we now find a multitude of emotional and cognitive problems, problems that used to be given other diagnostic labels or that were even considered within the range of normal. Doctors now have a more heightened awareness of autism and are diagnosing it with more frequency." In other words, high numbers do not necessarily mean new cases. If one in 150 children is on the autistic spectrum now, there may always have been this proportion, though we failed to recognize it.

According to Grinker, the classification of autism as a discrete disorder has always been problematic. Leo Kanner, the Austrian psychiatrist who in 1943 diagnosed a small group of children with the newly termed condition "infantile autism," placed his new diagnosis under the general umbrella of schizophrenia, which made it much more difficult for those with autism to be diagnosed correctly in the future. In the 1950s, children with autism were being labelled as schizophrenic and receiving the new treatment for this disorder: frontal lobotomy. As recently as the 1970s, individuals with autism were being diagnosed as schizophrenic and medicated accordingly. The term Asperger's syndrome did not exist in the English-speaking world until 1981, when autism expert Lorna Wing used the term to replace "psychopathy."

As Grinker points out, labels really do matter. Until 1991, there was no category of "autism" in the U.S. Department of Education's annual "child count" of children in publicly provided special education. Before that time, a child with autism was reported with some other disorder, such as "brain dysfunction" or "mental retardation." Once the school codes included autism as a category, the reported figures on autism dramatically increased. Grinker argues that this was not because more children were becoming autistic, but because more accurate data on children with autism was being reported.

Grinker speculates how autism may have been perceived in the past, offering scandalous, engaging anecdotes about children found in forests or spoken about in old fables: a "bear-boy" discovered in Lithuania in 1661, an Irish sheep-boy. Were these, in fact, autistic children who may have been abandoned by their parents and discovered, dirty and hungry, some time later?

We know that Bruno Bettelheim wrongly blamed mothers for "causing" autism in their children, but Grinker claims that Bettelheim's theories still have influence. "If,

one day soon, you find yourself in a remote part of the world," Grinker writes, "take a visit to a local library and look for books about autism. If they do have a book on autism it will almost certainly be Bettelheim's *The Empty Fortress*."

Grinker then moves on to discuss how autism is perceived in different parts of the world. In India, where most children who would be diagnosed with autism in the West are labelled as mentally retarded, or *paagol*, the Hindi word for mad, Indian women have to disregard tradition and even law in order to find a way to help. In Seoul, South Korea, the stigma of having a child with autism means many are hidden away and left completely uneducated. In Africa, a mother resists family pressure to visit a witch doctor to "treat" her teenage son. Everywhere we look, parents of autistic children are struggling against societies that either do not care or do not know how to respond to autism.

And yet, Grinker writes optimistically about the future. He has seen his own Isabel gain skills once thought unimaginable in a child with her degree of disability. He has witnessed the effectiveness of grass-roots efforts of good people from as far away as Cape Town and the Himalayas. With every passing day, autism is more visible, more acceptable. Those with autism have only just begun to show the world that they are capable of much more than anyone dared imagine.

Nobody is more interested in bringing the lives of autistic people to the forefront than Portia Iversen, author of *Strange Son*, a book that argues that even "low functioning" autistic people are anything but retarded. Like Grinker, Iversen's introduction to the mystifying condition was through her child. Iversen anguished as her son Dov failed to develop language or play skills, as he became increasingly distracted, more interested in dust specks than in human contact, and was finally diagnosed with autism.

Even worse, Dov failed to respond to interventions often used for autistic children. When years of play therapy and behavioural intervention did little to alter his condition, Iversen concluded that the only hope for Dov was through further advances in autism research. With a passion and determination that mark all of Iversen's efforts, she describes how she hit the research libraries for any clues to the bewildering, heartbreaking condition.

It wasn't long before she realized there were no answers for Dov in the scientific literature. Iversen explains that the first problem was that the scientists appeared to be in no great hurry to cure or even mitigate autism -- indeed, such an ambition was never even on the table. Furthermore, autism simply was not a government priority. While studies into Alzheimer's received \$60-million per year and breast cancer research \$600-million per year, the U.S. government allocated only \$5-million for research into the condition that affects as many as one in every 150 children.

The government's view on autism did not discourage Iversen. Together with her husband, Jon Shestack, she established Cure Autism Now (CAN), an organization of scientists, parents and clinicians committed to the acceleration of research into the causes, prevention and treatment of autism. Since its founding in 1995, Cure Autism Now has committed nearly \$39-million to research on autism, established the Autism Genetic Research Exchange, the first open-access autism gene bank in the world, and launched numerous outreach and awareness activities aimed at families, physicians, governmental officials and the general public.

But *Strange Son* is not about this heroic work. Autism is Iversen's subject, and her absorbing, speculative views on this baffling condition are at once compelling and controversial. Her focus is a teenage boy named Tito Mukhopadhyay, a brilliant young man from India who is severely affected by autism, yet is an eloquent writer with an IQ of 185. She arranges for Tito to be a keynote speaker for the annual CAN conference, a bold move considering Tito cannot speak intelligibly and his main form of communication is by pointing to letters on an alphabet board, a skill taught to him by his mother, Soma.

Having brought Tito and Soma all the way from India for the conference, Iversen then describes the terrible moment just before introducing Tito to the hundreds of people gathered. "Tito's eyes were now crossed as if he were staring at something mesmerizing inside his own brain. His rocking and flapping had accelerated so much that it looked like he might levitate at any moment." She thinks perhaps she has made a mistake, but Iversen is about to learn what she now wishes the world to know about autism: Despite appearances, despite the flapping and rocking and occasional odd noise, people with autism are "all there." Tito does not let his audience down. Pointing to a series of letters on his alphabet board, he taps out "I am honoured to be here" to the audience's thundering applause.

Throughout *Strange Son*, Iversen reminds us of the severity of Tito's condition. She describes Tito as constantly rocking or twiddling a pencil or flapping his hands in the self-stimulatory manner referred to as "stimming." Though she clearly admires and cares for him, her descriptions of his worst moments are somewhat harsh. I cringed when she described Tito as acting like an "alien" or a "wild beast" when he flies off into a rage.

But Iversen's purpose is to show that, however odd an impression an autistic person makes, it does not deny the possibility of an intelligence and awareness as sharp as any "neurotypical" person. If Iversen is unrelenting in her descriptions of Tito's difficult behaviour, she is equally adamant about his underlying intelligence, even his social intelligence. Tito may pace from one end of a room to another, or dash through Iversen's house rifling through drawers and closets, or stage moments of violence against his mother, or Portia herself, but he is paradoxically a most gentle,

intelligent, sensitive person. Iversen's (and Tito's) point is that you must not judge him by his outward appearance, his autistic appearance, the one that he, himself, tells Iversen "made the people close to you doubt you."

Tito's poetry, sprinkled throughout *Strange Son*, shows that he not only understands the nature of his condition, but also the way in which others perceive him. He is a thinker, a philosopher. His words challenge the commonly held notion that autistic people cannot understand and relate to another's feelings or thoughts, that they lack empathy or a theory of mind. The question Iversen is at pains to answer is whether Tito is a one-off, an anomaly, "his own disorder," as she puts it.

Tito's success in communicating his inner life and thoughts is due to the immense efforts of his mother, Soma, who refused to believe the experts when they told her that her son was retarded and uneducable. Soma begins to teach Iversen's son, Dov, using the same alphabet board and method she used so successfully with Tito. Eventually, Dov begins communicating in words and sentences, which he produces at an alarming and sophisticated fashion by pointing to letters. When asked by his mother what he has been doing for the past six years, during which he has been mostly unable to communicate, he taps out the word "listening."

We are led to believe that Dov, now 9, understands everything around him despite rarely appearing to notice his environment or other people. His newfound language, via the keyboard, suggests he has always been connected with his family, able to listen and learn, despite his constant stimming and inability to speak. Iversen argues that if both Tito and Dov can learn to communicate and engage through Soma's teaching, then others will, too.

Strange Son documents Iversen's exhaustive efforts to bring Tito to the attention of the scientific community and show them that we must not assume a lack of intelligence or empathy even among those autistic people considered to be "low functioning." The book argues that even those who manifest the condition in the most profound manner are deserving of our greatest efforts. Iversen does not explain Soma's teaching method (called Rapid Prompting Method, which Soma now teaches to children throughout the United States), but challenges commonly held views on autism and convinces us that, for the mother of a child with autism, there is no such thing as a hopeless case.

Marti Leimbach's most recent novel, Daniel Isn't Talking, features an autistic child. She lives in England.

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