



autism, through a social lens

by stephen poulson

Since the early 1990s the United States has seen a 10-fold increase in autism diagnoses. In 2007, 1 in 150 children were diagnosed with it, according to the Centers for Disease Control.

More than 40 percent of autistic children attending public school in 2006 spent their entire day in a special education classroom or attended a special school for children with disabilities, according to the U.S. Department of Education. These children have a disability severe enough that they probably have few prospects for meaningful employment after they leave school. But increasingly, many children are being identified as “high-functioning” autistics and are often mainstreamed, with significant help, into “regular” classrooms where they may not appear much different than their typical peers.

Sociologists are well positioned to weigh in on what, exactly, autism is, whether there really are more people today with autism than just a few decades ago, how autism is diagnosed and treated, and how families and other social institutions cope with

the challenges associated with it. Though sometimes reluctant to study biological and genetic disabilities, sociologists—especially in Western Europe and Australia—are beginning to make important contributions to both public and medical understandings of the conditions underlying autism and how to deal with them most effectively.

Although my own academic sociological expertise is in a different area entirely, over the last two years I’ve been observing an autistic boy, Sam*, and have come to see that sociology has so much more to offer the parents, caregivers, and researchers who want to understand what has been called the fastest-growing developmental disability in society today.

*not his real name

some basics

At its most basic, an autism diagnosis means an individual has an impaired ability to communicate and acquire social skills. It's usually associated with children and manifests itself initially in early stages of social development.

The severity of autism impairment varies among children, so it's characterized as a "spectrum disorder." High-functioning autistics and people with Asperger's syndrome are socially awkward and have difficulty understanding common social interactions, but they can learn to navigate the social world reasonably well. On the other end of the spectrum, people diagnosed with low social functioning autism may not even be able to speak.

A characteristic associated with autism is repetitive self-stimulating behavior, called *stimming*. The most common examples are rocking, pacing, repeating words, stacking objects, and banging one's head, among others. Of course, many people "stim" when stressed—I occasionally pace the floor—but autistic *stimming* seems to facilitate a deep withdrawal into the self.

The rocking, the pacing, the stacking, and the banging appears to help those with autism shut out the larger world and often provides them with great comfort. High-functioning autistics don't like change or surprises and they often develop mild *stims* that lower their distress when confronted with new situations.

Somewhat associated with *stimming* are the routines to which many autistics devote themselves. These sometimes include an unyielding abidance to "rules" that organize their lives, like a sequence of events that must be followed before going to school, before entering a room, or while riding in a car.

I believe people with autism are, for the most part, like everyone else—only quite a bit more so. Most people are nervous in new situations and when meeting new people, but many with autism find these circumstances debilitating.

When autistics are confronted with new situations, their rules often become more important. But, new situations usually require that rules be broken. This paradox can result in a circle of escalating distress for many autistics, which is why many avoid new places and new people.

It seems that many, in fact, regard themselves—and other people—primarily as objects. Put another way, they regard the objects and people in their lives as not much different from one another. This isn't meant to imply that people with low-functioning autism aren't often extraordinarily attached to their primary caregivers, but rather that their emotional attachment to objects and routines is usually quite intense. These individuals are unlikely to enter the workforce as adults. They often require extraordinary care—sometimes nearly one-on-one supervision during the day—to insure they're clothed, fed, and safe.

Most parents of autistics quickly learn the various stimuli



Photo by Scott Vaughan via Creative Commons

James Vaughan, now nearly 6, was diagnosed as severely autistic just after his second birthday.

in the world (automatic doors, for example) that are affronts to their child's sensibilities and cause melt-downs. The primary difference I associate with an autistic melt-down compared to a typical temper tantrum is that they often seem driven by extraordinary fear. They usually last until a child is successfully redirected, or perhaps decamped to a quiet place where they're given an object they love to manipulate.

Sociologists are beginning to make important contributions to both public and medical understandings of autism.

Asperger's is often considered a type of autism disorder, but some argue it should be treated as distinct from autism. While "Aspies" usually have some serious social delays, they can also be verbally precocious, have average or above-average intelligence, and are usually pre-occupied by a few narrow interests they're willing to talk (and talk, and talk) about to anyone vaguely interested. Sometimes they're referred to as "little professors." They usually attend regular schools where, despite some serious social and academic deficits, they may also be precocious at a few endeavors.

Tim Page, a Pulitzer Prize winning critic diagnosed with Asperger's as an adult, wrote recently in *The New Yorker*, " ...

if we are not very, very good at something we tend to do it very poorly. Little in life comes naturally—except for our random, inexplicable, and often uncontrollable gifts—and, even more than most children, we assemble our personalities unevenly, piece by piece, almost robotically, from models we admire.”

creating the autism spectrum

In medical lexicon, autism is described as “a complex syndrome without a uniform etiology.” In layman’s terms this means the causes of autism are diverse and unknown.

Although arguments associated with biological determinism and autism—particularly that a person’s genes “cause” autism—tend to receive the significant attention in the popular media, most scholars who study autism believe social and environmental factors have contributed significantly to the increase in diagnoses in the United States and around the world.

For example, it’s generally accepted among clinicians that expanded diagnostic criteria and greater screening is one reason for the increase in diagnoses. There are also indications that changes in obstetric medical technologies and practice may affect the increase. Still, these social factors probably don’t account for the entire 10-fold increase. There’s a strong correlation between the age of parents (particularly fathers) and the incidence of autism diagnosis among offspring. And, most experts assume biological predisposition accounts for the

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greater number of diagnoses among boys (although it should be noted girls are likely under-diagnosed for social reasons such as the fact that autism presents differently in girls than boys).

Sociologists and sociological thought have clearly played a role here. The few sociologists who study genetic predisposition and social life are often interested in what is commonly referred to as gene-environment inter-play. This is the idea that some genes, or combinations of genes, predispose people toward certain traits and characteristics. At the same time, experiences—particularly among young children whose brains are undergoing rapid development—play a crucial role in how these behavioral predilections play out. Ultimately, it’s social experience that turns on and refines a person’s social capacities.

Sociologist Peter Bearman heads one such promising research program. Funded with a \$2.5 million grant from the National Institutes of Health, Bearman takes the interactions between genetic predisposition and social structure seriously and investigates a wide range of social factors, including how changes in diagnostic criteria and social networks affect autism diagnosis. Bearman’s research could well help us better under-

stand how the interaction of genes and the social environment are contributing to the dramatic increase in diagnoses.

Another well-known sociological approach that may help in this regard concerns the increasing “medicalization” of society. This is primarily the idea that behaviors once considered common are now identified as disorders that require attention by professionals.

A reference point for much of this literature is David Rosenhan’s now famous experiment in which sane pseudo-patients, after gaining admittance to psychiatric hospitals, were never identified as “sane” by professional staff at these hospitals. This study demonstrated the malleability of professional medical opinion when diagnosing (and creating) psychiatric disorder. Closely associated with this perspective is the work of Peter Conrad on the medicalization of attention deficit/hyperactivity disorder (ADHD). More recently, Conrad and others have argued the increase in medical disorders—such as adult ADHD—is related to the increasing influence of Western pharmaceutical companies in shaping diagnosis and treatment regimes for a whole range of physiological conditions and disorders.

It’s likely the social creation of the “autism spectrum” has subsumed other types of diagnoses used in past. The more generic description of “mental retardation” was probably a common diagnosis a generation ago, for example. In this regard, one reason for the increase in autism diagnoses may simply

be that the public and medical professionals are now aware of it in ways they weren’t previously.

Some speech and occupational therapists I’ve met believe autism has become the diagnosis for children who have any measurable social or academic

delay. Indeed, many therapists and medical practitioners believe the increase in autism diagnoses has resulted from the recently created and gradually expanded criteria used to evaluate a range of behaviors.

autism and self

Because their goal is to teach children with autism to better understand social life and the world around them, clinicians who treat autism draw directly (if not always consciously) upon sociological ideas. In particular, treatments for autistic children employ George Herbert Mead’s insights about how we create a “self”—that we begin to do so by making comparisons to others during childhood play. Children with autism are exceptions in that they aren’t particularly interested in playing with, or evaluating behaviors, in the same manner as typical children.

Autistic children have considerable difficulty establishing “joint attention.” Most people, when they communicate, quickly fall into sync with each other. They establish eye contact and focus their attention on each other’s faces and body language. Autistic children don’t do this. Indeed, one marker



Photo by Scott Vaughan via Creative Commons

James has had two-and-a-half years of ABA therapy and his father Scott, who photographed him, said the results have been "amazing."

for the disability is that many don't understand non-verbal communication like waving hello or goodbye. When typical 2- and 3-year-old children sit in a room during story time at the library, most will intuitively be drawn to the person at the center of the room reading the story. An autistic child, assuming they aren't overwhelmed by the activity in the first place, may find something in the room to pay attention to, but it's less likely to be the storyteller.

Older autistic children, when viewing scenes from popular movies—a loud argument, a fight, a particularly passionate embrace—focus far less attention on people's faces, and particularly their eyes, than other children. They also take in the entire scene—tables, windows, doors, other objects in the room—more than typical people. As a result, many autistics can describe, sometimes in extraordinary detail, objects that appeared in the scene, but they miss much of the social interaction that takes place between the actors. Many autistics can be taught, or learn on their own, how to pay greater attention to people.

I was often alarmed when I began interacting with autistic children at just how little "self" many had constructed. I have observed one child, Sam, for nearly two years since his diagnosis with high-functioning autism at age 3. His general disposition—when not distressed—is amicable, but also very deliberate. He was far more "serious" than other toddlers. At 3 he didn't wave or say "hello" or "goodbye." He didn't point at objects he wanted. He rarely, unlike other children his age, imitated behavior. He didn't know how to ask a question, so he solved problems by using extraordinary complex methods of inductive and deductive reasoning. He had a reasonable vocabulary for his age, but he didn't understand the word "yes." He always referred to himself in the third-person. In short, he had significant delays in his acquisition of symbolic language.

Moreover, the world and the people in it, particularly when he was visiting a new place or meeting new people, often overwhelmed him. When this happened he had a repertoire of rel-

atively mild self-stimulating behaviors—he generally paced and repeated words—that he used to settle himself. The categories and rhythms Sam used to organize, navigate, and give meaning to his world—he was fascinated by shapes and colors—were so different than those of other children I thought he might not be able to form a meaningful social relationship as an adult.

treating autism

Treatments for autism are intense and expensive. At Sam's age, it's generally assumed that at least 20 to 25 hours of direct contact with a trained therapist, most often in one-on-one sessions for at least two years, is the minimum standard required. The specific approaches and therapies used to treat autism are contentious, but there's a clear record—beginning with the applied behavioral analysis (ABA) therapies conducted by Ivar Lovass in the 1980s—that treatment before age 3 can have a profound impact on an autistic's social functioning later in life.

Overall, the primary goal of all therapies, not just ABA approaches, is to teach autistics to establish joint attention. All aspire to engage autistic children in the social world, and to, in some manner or another, compel them to compare themselves to others. Often this involves teaching autistic children how to play more like typical children. Along the way, clinicians demonstrate that while social relationships can be contentious, sporadic, and random, they're satisfying, too. The most successful treatments teach, often in an intellectual manner, a sense of emotional empathy.

In the best cases, school systems have programs that provide the bulk of this therapy—in Sam's case, which is not necessarily typical, he received nearly 16 hours of therapy per week at school. Autism spectrum disorders, though, aren't covered by most health insurance providers, at least in Virginia where he lives, so the additional 10 hours of therapy each week was provided by Sam's family at a cost of \$8,000 annually. Tuition at private schools in Virginia that provide ABA therapy to lower-functioning autistics with a near 1-to-1 student-therapist ratio cost as much as \$80,000 per academic year. (It probably doesn't take a sociologist to see these numbers and begin thinking about inequalities in access to treatment that might come into play in different communities and contexts.)

Sam was largely taught to focus on people by sitting at a table across from a therapist who demanded that he pay attention to her. She used snacks, toys, and other reinforcers to help the process along. Once he gained this skill he was largely released from the "table-work" and, with the help of aides, practiced interacting with other children his age. Over time he was slowly immersed into a Head Start classroom where, with the help of aides, he learned to play with others and use the social skills he was being taught. He's still shadowed by aides, but he spends more time in the typical classroom than the special ed classroom. He also took part in a coordinated battery of other group activities—play groups, youth soccer, gymnastics,



Photo by Scott Vaughan via Creative Commons

Scott says James enjoys the time he spends with his therapists and teachers.

and swim lessons—to reinforce the therapy he received.

So, for the past 20 months Sam has been pushed, drilled, perhaps even coerced, into becoming a more social person. As he approaches his 5th birthday, his conversational style is different than other children's, but his social interactions are often reciprocal and, for the most part, increasingly "normal." While most clinicians are careful to tell parents that children can't be "cured" of autism, there's increasing evidence some high-functioning autistic children—particularly those who receive similar interventions at an early age—do age-out of many behaviors associated with autism.

how families cope

To date, some of the best sociological studies of autism have focused on how families cope with caring for autistic children. Sociologist David Gray has conducted one of the few longitudinal studies of family coping. He conducted 28 interviews with parents roughly 10 years following their children's initial diagnosis and treatment.

The highest levels of self-reported psychological and emotional distress for parents occurred when they were first identifying their child's disorder and attempting to secure treatment services. While parents, roughly 10 years later, still experienced stress because of their children's autistic behaviors, two-thirds were less so than 10 years before. Moreover, many said other family members and friends had become far more sympathetic and helpful over time. Not surprisingly, the level of an autistic child's social functioning appears related to the stress parents report experiencing. For families whose children were often violent or aggressive, their distress was still considerable.

Gray found noticeable gender differences in how parents responded to autistic children. For example, many mothers reported leaving full-time employment to care for their autistic child. No fathers (who were under-represented in the study) had interrupted their careers. And while life gets easier for many families that raise autistic children, many parents still reported experiencing social stigma, mothers far more than fathers. Some

found it difficult to go into public with their children because their child's behaviors embarrassed them. On occasion, some were rebuked by strangers for allowing their child to act out in public. Often, other family members, and even strangers in public places, attributed the cause for an autistic child's behaviors to bad parenting. Some parents reported they were excluded at times from family and social events because of their child's disability. At the same time, this was less commonly reported during follow-up interviews 10 years later.

Initially very concerned about how their typical children would be affected by having an autistic sibling, 10 years later most parents reported siblings generally experienced little social stigma from their peers and had learned to accommodate their autistic sibling's disability.

One other important area of concern for parents of autistic kids was their child's prospects once they became adults. In this respect, some had hoped their children with autism might be employable, but were increasingly concerned about the lack of occupational programs available to prepare their children for work. Many assumed they would continue to care for these children well into their adulthood.

other sociological dimensions

Parents have often been at the forefront of activism and organizing around issues related to autism. Similar to other disability movements (such as activism associated with securing treatment for post-traumatic stress disorder), an increasing number of social movement organizations—Autism Speaks is one—currently champion more research on autism-related causes. Some of these organizations focus on eliminating medical practices they believe contribute to autism, others primarily provide the public with information about recognizing early signs of autism, given the efficacy of early intervention programs.

More to the point of treatment, a number of autism organizations are trying to secure legislation that mandates insurance companies provide coverage for autism spectrum disorders. Some states have already mandated coverage, but the majority don't. Activists are also concerned with the "free and appropriate public education" provision of the Americans with Disabilities Act. Under this provision, beginning at age 3, autistic children (mentioned specifically in the law) should be provided with an appropriate education tailored to their specific disabilities.

Not surprisingly, given the costs of these interventions some school districts don't provide these services. In fact, it's been common for districts to simply refuse to identify children as autistic because officials regard the cost of providing services as too expensive. In other cases, autistic children are simply placed in existing programs that aren't tailored to their disabilities. As a result, many families with autistic children move to school districts that have established autism programs. Parents of autistic children are suing school boards more often now for ignoring this law, and they're often winning.

Activism like this gives rise to a whole range of questions medical and organizational sociologists are well-positioned to take up: who determines which treatments children receive in the absence of health care coverage? How we do deal with basic inequalities in access to treatment? And perhaps even more provocatively, why is it that some parents embrace the diagnosis of autism while others resist or even fight the label?

Autism raises broader questions about fundamental assumptions concerning what's different and what's normal, about what's genius and what's deviance. A common and particularly provocative debate among people with Asperger's and autism, for example, concerns the degree to which they should be forced to conform to social norms established by the "neuro-typical."

Many with high-functioning autism and Asperger's, while recognizing their differences compared to the neuro-typical, resent the specific labels associated with their conditions and argue against the characterization that they have a disability. Some individuals who self-identify as "neurologically non-typical" are becoming outspoken advocates against the use of genetic testing on fetuses on the assumption that screening for autism and Asperger's—like the current screening for Down syndrome—could become commonplace in the future. Others argue prominent scientists and innovators—Albert Einstein or Bill Gates, for example—would likely be on the autism spectrum, and insist autistic reasoning is, in some ways, superior to typical reasoning.

Here it's also interesting to point out that clinicians who treat autistic children sometimes spend time navigating the criminal justice system because of the idiosyncrasies and compulsions many autistics have. For example, some are fanatical "collectors" and when they see something they want—in a store, in a neighbor's yard—it's hard to resist adding it to their collection. Autistics are also easy marks for criminals and are sometimes unwitting accomplices to crime due to their social naiveté. Autistics are bullied more often—a neighbor of mine who once worked with autistic children received routine calls about a young man, usually mild in disposition and temperament, being constantly provoked on his bus ride home from school. When this happened he inevitably grew agitated, would scream profanities at his bus driver, and then literally force him—he grabbed the steering wheel more than once—to stop the bus. He was often miles from his house, but he would disembark and walk along the roadside while screaming profanities until someone he knew came and picked him up.

Was this young man "deviant?" Were his actions violent? It's often these types of scenarios—generally an autistic's increasing distress accompanied by an escalation of inappropriate behavior like throwing objects, hitting themselves, or screaming—occurring in a public place that cause some to end up in the courts. Given that many are sensitive to noise, pub-

lic places, and crowds, otherwise simple excursions—a holiday vacation that requires air travel—can result in uneasy confrontations with security personnel. As a result, it's increasingly common that law enforcement officials are trained in how to handle disturbances created by autistics in public places.

Sociological thinking about identity underlies a great deal of autism diagnosis and treatment. Sociologists are beginning to make important contributions to autism research by situating it in broader social contexts, including the institutions that

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do (or do not) assist those with the condition and the inequalities that may come with access to treatment.

Still, the most basic questions about autism and the broader implications they raise are the most intriguing to sociological readers and researchers. And here, more than anything, is an opportunity to have a greater understanding of interactions between socialization and genetic heritability. Perhaps as sociologists spend more time watching how children with autism are taught to navigate the social world they'll find interesting examples that show how socialization—despite disability—still determines much of who we become.

recommended resources

Simon Baron-Cohen. *Mindblindness: An Essay on Autism and Theory of the Mind* (MIT Press, 1997). An accessible book by a psychologist that explains why autism is important to understanding human psychology.

Peter S. Bearman, Molly A. Martin, and Sara Shostak, eds. "Genes and Social Structure," *American Journal of Sociology* (2008) 114 (1): 1–316. A collection of studies that demonstrate approaches used by sociologists who study gene-environment interplay.

Temple Grandin. *Thinking In Pictures and Other Reports from My Life with Autism* (Vintage Press, 1996). The first popular autobiography written by a person diagnosed with autism as a child.

David Gray. "Ten Years On: A Longitudinal Study of Families of Children with Autism," *Journal of Intellectual & Developmental Disability* (2002) 27 (3): 215–222. A study that investigates how living with autistic children affects family life over time.

Roy Richard Grinker. *Unstrange Minds: Remapping the World of Autism* (Basic Books, 2007). A broad overview, written by an anthropologist with a distinctive sociological bent.

Ami Klin, Warren Jones, Robert Schultz, Fred Volkmar, and Donald Cohen. "Visual Fixation Patterns During Viewing of Naturalistic Social Situations as Predictors of Social Competence in Individuals with Autism," *Archives of General Psychiatry* (2002) 59: 809–816. A study that demonstrates autistics have difficulty reading faces and understanding people's emotional states.

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