

Answer, but Not a Cure For a Social Disorder That Isolates Many

Continued From Page A1

ter for Autism in Stony Brook, N.Y. "It is thought to be your fault, you should just shape up, work harder, be nicer. The fact that your brain actually works differently so you can't is not universally appreciated."

Some Aspies interviewed asked to remain anonymous for fear of being stigmatized. But, with the knowledge that their dysfunction is rooted in biology, many say remaining silent to pass as normal has become an even greater strain.

"I would like nothing better than to shout it out to everyone," a pastor in California whose Asperger's was just diagnosed wrote in an e-mail message. "But there is so much explanation and education that needs to happen that I risk being judged incompetent."

Some are finding solace in support groups where they are meeting others like themselves. And a growing number are beginning to celebrate

Researchers say autism spectrum disorders are a result of a combination of perhaps 10 to 20 genes, plus environmental factors, that seem to cause the brain to exhibit less activity in its social and emotional centers. Unlike people with classic autism, which is often accompanied by mental retardation, those with Asperger's have normal language development and intelligence. First identified in 1946 by the Viennese physician Hans Asperger, the condition was little-known until it was added to the American psychiatric diagnostic manual in 1994. Only in the last few years have mental health professionals become widely aware of it.

The degree to which someone is affected may correlate with how many of the autism genes he or she has, some researchers say. About one in 165 people are thought to be on the autistic spectrum, although estimates vary.

The recent spike in diagnoses of autism in people who are generally



Tim Shaffer for The New York Times

Some are finding solace in support groups where they are meeting others like themselves. And a growing number are beginning to celebrate their own unique way of seeing the world. They question the superiority of people they call "neurotypicals" or "N.T.'s" and challenge them to adopt a more enlightened, gentle outlook toward social eccentricities.

Asks the tag line of one online Asperger support group: "Is ANY-ONE really 'normal?'"

Discovery

Finding Reason For Social Gaffes

In recent years, a growing awareness about autism has led to a sharp increase in children receiving special services for their autism disorders. But for many adults who came before them, the process of discovering the condition has been haphazard.

Mr. Miller, a senior academic librarian at the University of Wisconsin, Milwaukee, had searched for years for an explanation for what he saw as a personal failing, buying stacks of self-help books. Many others sink into depression, their conditions misdiagnosed, or struggle without any help.

Now, autism centers intended for children are being flooded with adults who suspect they have Asperger's. Since the condition runs in families, psychologists treating autistic children are often the ones diagnosing it in parents or relatives.

Often the new diagnoses involve people who for years have been deemed rude, clueless or just plain

the autistic spectrum, although estimates vary.

The recent spike in diagnoses of autism in people who are generally able to function in society has prompted others to suggest that it is an excuse for bad behavior or the latest clinical fad. But psychologists and researchers say they are simply better able to recognize the condition now. While many people may have a few of the traits and just one or two of the genes, to qualify for an Asperger's diagnosis they typically must have developed obsessive interests and social difficulties at an early age that now significantly impair their ability to function.

Carl Pietruszka, 52, said that being found to have Asperger's had been a blow to a long-held fantasy. "It's been my hope for years and years that if I keep working at it, I'll find a strategy that will fix things, that if I practice enough, it'll be O.K.," Mr. Pietruszka said. "Now I know I'm working with Asperger's, which is going to be an ongoing thing. It'll get better, but it's not going to be O.K. That has me seriously bummed out."

Mr. Pietruszka, who was laid off from four engineering jobs over a decade, said colleagues had often ribbed him for being too serious and "not getting it."

"It doesn't make you feel good,"



Gresham O'Malley, left, and Robert Britchkow in an exercise in which they try to converse without lapsing into silence, as Mary Cohen observes.

he said. "It festers."

Instead of looking for work with a company where he would have to navigate office politics again, he has set up his own business as a home inspector in Harleysville, Pa., where clients have complimented his thoroughness.

Inspiration

Trying to Learn Hidden Curriculum

Pretending to be normal, even for a few hours, is mentally exhausting, many Aspies say. But for some, the diagnosis is an inspiration to master what autism experts call the hidden curriculum: social rules everyone knows but could never say how they learned.

A class taught by Mary Cohen, a psychologist at the University of Pennsylvania's new clinic for adult social learning disorders, is crowded with people whose conditions are newly diagnosed. The subject at a

recent session was basic conversation. As the class watched from behind a two-way mirror, pairs of students tried talking to each other without lapsing into silence.

Then came the review: had it been a dialogue, or had someone gone on about the early history of Russia a bit longer than necessary? Did they lean in? Eye contact, Dr. Cohen cautioned, should be regular but not "like you're boring a hole through them." Moving the eyebrows can help.

Gresham O'Malley, 33, a computer support technician, said he hoped the class might make it easier for him to find a girlfriend.

But classes like Dr. Cohen's are few and far between. Mostly, parents, siblings and spouses are left to explain such everyday social rules as which urinal to select (preferably not the one next to another that is occupied) and why a prospective employer does not have to be told about a punctuality problem.

At a support group for parents in Dix Hills, N.Y., the two-hour meeting runs late as more than two dozen participants trade notes about adult children who always had trouble making friends but now face more serious problems. After flubbing dozens of job interviews, many spend their days playing video games.

"Don't you get the advice, 'Give him a kick in the pants?'" one father asks.

"Exactly," answers a mother. "You're spoiling him."

"Our relatives will say, 'He looks

member to form strategies with Mr. Jorgensen. In public meetings, they agreed, someone would throw a pen at him when he was going too far. Privately, they would tell him directly, rather than hint at it in ways he might not understand.

"They cared about me and I sensed that," Mr. Jorgensen said. It may have helped, too, that he is what Mr. Keith describes as "one of the best guys that I've ever worked with" at finding defects in the design of software. In the argument with their boss, Mr. Keith said, Mr. Jorgensen was clearly undiplomatic. "But he was right."

Not everyone is finding such enlightened responses.

When John Hatton, 40, of Boston, began to tell friends about his Asperger's diagnosis, they were skeptical.

"Almost everyone I contacted about this were either sort of perplexed or — I don't want to say hostile," said Mr. Hatton, who said he had been fired from more than 26 jobs over the last two decades and now received federal disability assistance. "They thought I had found an excuse or something."

Results

Saving Marriages, Ending Others

For troubled marriages, the diagnosis can be pivotal.

"I would just go change the clothes," she said. "If I want affirmation I need to say, 'I'm feeling a little insecure, can you give me reassurance?'"

United by their newfound identity, Asperger adults, so used to being outcasts, are finding themselves part of an unlikely community. Through online and in-person support groups, many are for the first time sharing the pains and occasional pleasures of feeling, as one puts it, "like extraterrestrials stranded on earth."

Emboldened by the strength of their numbers, they are also increasingly defying, or at least exploring, how to bend the social rules to which they have tried so hard to adapt.

Some brag about their high scores on the "autism quotient" test, developed by Cambridge University as a measure of autistic traits in adults. "What's your 'Rain Man' talent?" asked a recent subject line on an Aspie e-mail discussion list, referring to the 1988 movie starring Dustin Hoffman as an autistic savant. Answers included perfect memory for phone numbers and "annoying people by asking awkward questions."

At a recent meeting of the Manhattan adult support group, a woman explained that she "just wanted to see if I fit in the group."

A longtime member replied, "None of us fit in with the group."

Neurotypical friends had been invited to serve as "expert" panelists to field questions on the evening's topic: flirting. But the best advice

Often the new diagnoses involve people who for years have been deemed rude, clueless or just plain weird because of their blunt comments or all-too-personal disclosures. They typically have a penchant for accuracy and a hard-wired dislike for the disruption of routine.

Unusually sensitive to light, touch and noise, some shrink from handshakes and hugs. Humor, which so often depends on tone of voice and familiarity with social customs, can be hard for them to comprehend. Although many have talents like memory for detail and an ability to focus intently for long periods, Aspies often end up underemployed and lonely. Unlike more severely impaired autistics, they often crave social intimacy, and they are acutely aware of their inability to get it.

Those with the condition often develop a passion for a narrow field that drives them to excel in it, but fail to realize when they are driving others crazy by talking about it. And they are reflexively honest, a trait that can be refreshing — or not.

On a recent afternoon at the Center for Brain Health at New York University, Louise Kavaldo, 57, who received a diagnosis of Asperger's last month, prepared to take some cognitive tests.

"Do you think my shirt is too tight?" she asked Isabel Dziobek, the researcher.

"No," Ms. Dziobek replied. "I like the way the green goes with your hat."

"Well I think your shirt is too tight," replied Ms. Kavaldo, who has a B.A. in sociology and works in early childhood education. "I think it's unprofessional."



Annie Marie Musselman for The New York Times

After Eric Jorgensen was found to have an autistic disorder, it helped smooth out the rough edges of his relationship with his wife, Janet.



Tim Shaffer for The New York Times

Larry Berman, with his wife, Laurie, is among the parents who complain about the lack of tolerance for children with autistic disorders.

asks.

"Exactly," answers a mother. "You're spoiling him."

"Our relatives will say, 'He looks fine to me,'" adds another parent. "And he does look fine. That's not the point."

Some of the anger is directed at mental health professionals who as recently as two years ago failed to identify Asperger's when they saw it. But some parents also complain about the lack of tolerance for "weird" kids, and the weird adults they grow up to be.

"If my daughter was in a wheelchair, people would be opening doors for her," said Larry Berman, a salesman who attends a similar group in Philadelphia. "Wouldn't it make a quantum difference if instead of it all being on our kids to flex to meet the rest of the world," Mr. Berman said, the rest of the world would "meet them halfway?"

Aware that their missteps seem all the more shocking because they show no visible signs of disability, some Asperger people are choosing to disclose their diagnosis in hopes of heading off social mishaps — or because they are in the middle of one.

When Eric Jorgensen, a programmer at Microsoft, confronted his boss's boss in a group meeting, his colleagues told him later that they were cringing, and he received a reprimand from his supervisor.

"I talked to my boss and said, 'This is an example where I need help,'" said Mr. Jorgensen, who realized that he had Asperger's after his son's diagnosis of autism. Mr. Jorgensen's boss at the time, Ed Keith, had never heard of Asperger's. But he assigned a team

Ending Others

For troubled marriages, the diagnosis can be pivotal.

One Los Angeles woman remembers the precise angle of the sun coming through the library window when she first read about Asperger's. She had wanted to leave her marriage for years but blamed herself for failing to make it work. When her husband refused to discuss whether his condition contributed to their problems, she said, she was able to leave without guilt.

But for Janet and Eric Jorgensen, the diagnosis helped smooth out the rough edges. Ms. Jorgensen, attending a conference to learn more about her autistic son, said it was like "a light coming on" when she heard that adult family members often were given diagnoses only after a child had been identified as being on the autism spectrum.

"It just sort of hit me, 'That explains Eric,'" she said.

He still says things that are callous, at least on the surface.

"She'll say something about how terrible her clothes look," Mr. Jorgensen explains. "I'll say, 'Yes, honey, those are terrible-looking clothes,' when really she's wanting some affirmation that her clothes don't look terrible."

At those moments, Ms. Jorgensen now tells her husband that he is acting like an "ass burger," a running joke that defuses anger on both sides. But such exchanges have mostly disappeared because Ms. Jorgensen knows that she is unlikely to get what she wants that way.

Learning to be more direct herself was not so horrible.

"None of us fit in with the group."

Neurotypical friends had been invited to serve as "expert" panelists to field questions on the evening's topic: flirting. But the best advice came from the Aspies.

"I find that sometimes shutting up and just not talking often makes them think you're a good listener when in fact you're just not talking," said one participant.

Michael J. Carly, the group's leader, suggested: "How about, 'Hi, I'm Michael. I really stink at flirting but would you like to go for a walk to the library or something?'"

The next generation of Asperger's adults may already be benefiting from an earlier diagnosis. After the condition was diagnosed in her son Jared at age 12, Nancy Johnson of Edmonds, Wash., was able to persuade his public school to provide a full-time aide who coached him on social skills for the next four years. Ms. Johnson learned how to rid Jared of some of his behavioral quirks, like his tendency to walk over to other tables in restaurants to get a better look at the food.

Ignoring his mother's concerns about his special interest ("I wouldn't have picked lizards," she says) Jared, now 19, has his path to becoming a renowned herpetologist all mapped out. After a rough time in middle school, where he says he finally learned the social consequences of picking his nose in public, he describes himself as "practically popular."

"It does seem like people with Asperger's, once they click, have a lot of advantages in life," Jared said. "It's like we stay tadpoles for longer, but once we're ready, we're no less of a frog."