

DIFFERENT FOR DECADES

Adults with Asperger Syndrome Strive to Fit In

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Geeky. Clueless. Loner. Loser. Just plain odd.

All their lives, they have heard these words and society's ruthless verdict that, try as they might, they can never achieve that indefinable state of "fitting in." Finally these people are hearing a new word: Asperger's. At long last, medicine has a label for their quirks.

"Before I got a diagnosis, even I thought I was crazy," said one man attending a Middlesex support group. "I thought I was weird, strange. And I didn't know why."

Asperger Syndrome is a neuro-biological disorder, a specific form of high-functioning autism in which the individual has difficulty picking up social cues from others. It accounts for roughly 9 percent of autism cases, according to the New Jersey Center for Outreach and Services to the Autism Community. Males are four times as likely to have the lifelong disorder as females.

Unlike the classically autistic, however, "Aspies," as some of them like to call themselves, are highly verbal. Often they can't stop talking about bizarrely narrow pet interests.

"Words are their lifeline. They talk before they walk," said Fred Volkmar, a child psychiatrist at the Yale Child Study Center and co-editor of "Asperger Syndrome" (Guilford Publications, \$55). "The problem is their deficits are masked by their verbal skills." Since other people don't perceive a true disability, they assume the Aspie's conversational style is willful, or that he's being thoughtless or just plain difficult.

"When you look normal, people expect you to be normal," said Sue Shikiar of South Orange, whose brother wasn't diagnosed until he was in his early 50s.

It also differs from regular autism in that Aspies usually crave social interaction and are astute enough to notice — and rue — their inability to secure it.

The disorder gets its name from Hans Asperger, a Viennese medical student who wrote his 1944 thesis about a group of highly intelligent boys who had extreme difficulty making friends. But it was not recognized as an official diagnosis in the United States until 1994.

In the last decade, diagnosis of school-aged children has become commonplace; rare is the school district untouched by Asperger's. That first wave of Aspies is just now entering young adulthood, having reaped the benefit of everything from occupational therapy to social-skills training.

They will most likely have sunnier futures than today's older Asperger adults, some of whom weren't diagnosed until well into middle age, say experts. "We know for autism that early diagnosis can lead to significant improvement for them, and there's every reason to believe the same will be true for Asperger's," Volkmar said.

This is not their story.

Instead, it is about adults who weren't diagnosed until they were 30, 40 or 50. Growing up, they endured decades of misdiagnosis and misunderstanding. They may be the 53-year-old who still lives at home with his worried parents; the 30-year-old overnight stock boy at the supermarket whose co-workers relentlessly play mean-spirited jokes on him; or the twentysomething man who is enthusiastically teaching himself one foreign language after another, while working just 12 hours a week at the local dollar store.

On the mildest end of the disorder are people who are married and gainfully employed at sophisticated jobs — yet still are perceived as eccentric, odd or “just a little off.” They have no need to attend any support group. They may include, as one expert joked, “the senior faculty of any major college math or engineering department.”

“Many of these people are pretty successful, as artists, mathematicians, scholars,” said Walter Zahorodny, assistant professor of pediatrics at New Jersey Medical School, Newark, and director of New Jersey's “Answers for Autism” survey. “Many do achieve a career and can be successful in their occupation. They're successful in most of the ways we gauge success, with jobs and families.”

Yet, on the other end are severe cases, adults who can't even attend an Asperger's support group because of their social discomfort. At a recent meeting in Freehold, one mother arrived by herself, saying of her adult son, “He wouldn't be able to do the eye contact that all of you have.”

Aspies have their strengths: They are eager to please; have fantastic rote memories; follow rules exactly, and often are skilled in math, writing, music or computers.

Undercutting those strengths are their rigidity about rules and routines; clumsiness, hypersensitivity to certain textures, foods or noises, or their overriding inability to “read” others. Unable to monitor the emotions of others, they may also have trouble taking their own emotional temperature, so to speak. They may ignore uncomfortable emotions until the build-up triggers a meltdown.

Yet there are infinite ways these traits can combine — leading people in the autism field to say, “If you've seen one Asperger's ...you've seen one Asperger's.”

There is no specific course of treatment or cure for Asperger's, which is a lifelong condition, according to the National Institute of Neurological Disorders and Stroke. While Aspies have a better prognosis than those with other forms of autism, they are at increased risk to develop mood problems such as depression and anxiety.

Over the years, adults with Asperger's have had neither help nor understanding. Most were subjected to hideous amounts of teasing, bullying and outright social ostracism when growing up. As a result, as adults they are the kind of people who, when they receive an invitation to their high school reunion, can't throw it in the trash fast enough.

“It didn't matter what I was doing, I was picked on. I was thought of as the weird one. It didn't matter what I said,” said a 29-year-old Piscataway man who attends a social-skills class once a week. “Even when I didn't say anything, they'd pick on me for not saying anything. You couldn't win.”

Early intervention? Sorry, too late. Theirs is a tale of lost opportunities.

And what of their parents? Most have seen it all, from discouraging school reports to misdirected treatments. Many endured the implication that they themselves had separation issues with their clingy, dependent children.

Florence Cohen, of Marlboro, heard both criticism and praise for her handling of her son — both of them off the mark. When he was originally diagnosed with classic autism, she was wounded by the scientific community's theory that she was a “refrigerator mom” whose coldness was partly to blame.

“That was devastating. Just when you needed to be strong, it made you weak,” she said.

Yet when her son succeeded academically, she was praised for her great ability to extract such performance from an autistic student. Both verdicts were inaccurate, a reflection of medicine's bewilderment in the face of kids who were betwixt and between the diagnostic categories. (Her son now lives in a supported apartment and works in a mailroom.)

These parents are a special group whose peaceful acceptance of their children contrasts with typical modern parenting, with its emphasis on relentless striving and improvement of one's progeny. Abraded by decades of disappointment, what is left is a hard kernel of calm love.

In most illnesses, medical science notices it first in adults, then gradually realizes it may strike children as well. Asperger's has been the reverse — noticed first in children and only belatedly in adults. In fact, support groups report it is common for an adult to realize he has Asperger's only after the school system has diagnosed one of his children.

“No one knows who they are or what they are,” said Shikiar. “They aren't in the school system, so who's going to diagnose them? The supermarket clerk? The guy at McDonald's?”

Regardless of age, one of the telltale traits of the disorder is the penchant for a deep interest in a narrow topic, almost to the point of excluding normal interests. Aspies might memorize train schedules, movie dialogue or everything there is to know about the solar system. Indeed, in the early years, parents might believe their child is precocious.

What makes this preoccupation cross the line is the Aspie's inability to sense when others have become bored by the topic.

Volkmar, the Yale autism expert, tried to explain the difference: “If a kid has a rock collection he keeps under his bed, no problem. If the only thing he's able to focus on is rocks, or if the family has to drive 1,500 miles out of its way to see an unusual rock formation, that's Asperger's.”

Volkmar tells of one boy so fixated on the Weather Channel that the local school superintendent would consult him before calling a snow day. “The problem was that all the kid could talk about was the weather,” he said.

In adolescence or beyond, if that obsession is another person — whose disinterest the Aspie doesn't or can't grasp — the result can look very much like stalking.

In children, some of these traits can still be seen as charming. In Hans Asperger's time, it was called the “little professor” syndrome, for example, which implies a certain cuteness.

But society is far less forgiving of those same traits in adults, who, it is assumed, should have figured out the unwritten social code by now. In fact, science is only now beginning to understand what the disorder looks like in adults. (After all, Asperger himself didn't bother to consider the future of the little boys he studied.) Many health and social services professionals serving adults still haven't heard of it.

To combat that ignorance, a support group for Asperger's families has written a pamphlet it intends to distribute to clergy, marriage and family counselors, and neurologists — the frontline people who might end up diagnosing an adult. The pamphlet, “Living in a World They Don't Understand,” will also be sent to every state legislator, said Mary Meyer of Allendale, coordinator of an adult chapter of ASPEN, the Asperger Syndrome Education Network.

Given that there is no cure, what difference can a mere diagnosis make? It carries practical benefits. Adults with Asperger's can qualify for Supplemental Security Income through Social Security and can apply for government benefits such as vocational job coaching or supervised housing — although that has a very long waiting list.

It also helps them confront the behavioral obstacles that keep them from achieving success in the two arenas Freud called “the cornerstones of our humanness”: love and work.

“They want to find someone to love and who loves them, and they want to have a meaningful career,” said Jed Baker, a clinical psychologist who runs an adult Asperger's social skills group at his office in Somerset. There, clients discuss problems they're having at work or in relationships.

At a recent session, Matthew Loscialo, 26, of Lebanon, said his goals were “to learn to say the right stuff so I don't lose my job.” (He tends to overwhelm both his boss and the customers with enthusiastic conversation.) He also wants tips on getting a girlfriend.

Another young man, who works at a developmental disabilities center, said he has mixed emotions when he sees young Asperger's kids getting the therapy he never received as a child. He's glad they're getting it, but envious, too.

On the wall is a laminated chart explaining how to converse. “Getting to know new people” advises them to ask about work, hobbies or family. “Keep conversations going” tells them to ask follow-up questions, like “How?” or “What else?”

Some sit in silence; others can't seem to stop talking. Baker gently guides both types towards the normal give-and-take of a group discussion.

If someone in the group has a job interview, they do a mock run-through. When one of their number gets a job, they all go out for pizza. “Many of our members report this is their only outlet socially,” Baker said. “Most of the adults have a long history of being teased and picked on. It's very healing when they find people who are very tolerant.”

It is harder to work with adults, Baker reports, simply because they're on their own during the week. With children, parents and teachers report problem areas to him and can prompt their children to use the new skills they've learned. The adults have to remember themselves; Baker sends several on their way with little “cheat sheet” scripts for tricky situations.

“It turns out you can't teach everything, so you have to go for the biggies,” said Yale's Volkmar, who does similar social-skills therapy. “But if they're motivated, and the teacher is motivated, you can teach them a lot,” he said.

As for the obsessive hobbies, Aspies of any age can be taught to ascertain whether they are boring people. “The kid who talks about rocks can be taught to ask every five minutes, ‘Are you getting bored with all this rock talk?’ ” Volkmar said. (So far, however, medicine has found no way to free that same kid from the urge to talk about rocks.)

At the very least, a diagnosis also helps their loved ones understand them better. “Information is golden in this disorder, it truly is,” said Karen Rodman, who founded the Cape Cod-based Families of Adults Afflicted with Asperger's Syndrome. Her husband's late-in-life diagnosis, in 1999, helped her understand that his detachment and isolation weren't intended to hurt.

“Asperger's is a dictator,” she said. “They don't have a choice.”

It also helped her stop expecting things he was incapable of giving. In that respect, the diagnosis improved her life by changing her, not him. “The families have to change their expectations — and that's a heck of a thing to ask of them,” she said.

Some adult Aspies are beginning to take control over the common goal of improving their social lives. One Milltown support group just for Asperger's people (minus their relatives), Autism Spectrum Adult Issues, recently broke from its typical agenda of group discussion to schedule a night out bowling.

But might it simply be too late for intervention to help? The experts are assuming it isn't.

“Things get more ingrained when people get older. But I wouldn't want to give up on anybody,” said Volkmar. “With many of these people, they haven't had any intervention, so how would we know?”

