

QUOTE OF THE WEEK: If you have a significant interest in trains, I can almost guarantee you're on the [autism] spectrum. [SEE PAGE 12]



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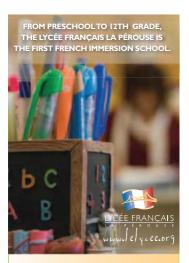
FULL SPECTRUM

How changes to autism classification will affect 'Aspie' education

by Jordan E. Rosenfeld

since 1944, when Austrian pediatrician Hans Asperger first noticed a set of characteristics in children that would eventually bear his name, Asperger's syndrome has gone from a largely misunderstood condition to one that has captured the attention of popular culture, showing up on television shows like *Parenthood*, in best-selling novels and in films (many feel that *The Girl With the Dragon Tattoo*'s Lisbeth Salander is textbook Asperger's).

While Asperger's syndrome, considered by professionals to be on the autism "spectrum," has made its way into the social consciousness, ironically, those with the condition, who call themselves "Aspies," have trouble understanding and using basic social cues. Because of Aspies' obsessive interests in specific subjects, and oftentimes repetitive behaviors, socializing can be an awkward, even agonizing, experience—many are bullied and teased—and they can prove challenging for teachers who don't have experience dealing with their unique brains.



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Please contact the admissions office to register to our next Open House admissions@lelycee.org | 415.661.5232 Yet, while Aspies may have difficulties communicating in "socially acceptable" ways, they do communicate, and often articulately. Many Aspies (and high-functioning autistics) have high I.Q.s and are extremely bright. Many marry and have children and successful careers.

Those are the lucky ones. For other Aspies, because of the limits of public schools, a lack of special education among teachers and the cruelty of peers who don't understand them, they may spend years struggling with the conundrum of being a bright person who nonetheless struggles or even fails in school and work.

The diagnosis first entered into the American Psychiatric Association's "bible"—the Diagnostic and Statistical Manual of Mental Disorders (the DSM)—in 1994 and since then, Asperger's has always been considered a separate but "similar" developmental disorder to autism, with which it shares many traits. Before then, Aspies were often misdiagnosed with conditions ranging from ADHD to schizophrenia.

Now, a proposal to remove Asperger's as a separate diagnosis, and lump it into the generic "autism spectrum disorder," is causing concern among educators and Aspies.

Janet Lawson, MFT, is founder and CEO of Autistry Studios in San Rafael, a private nonprofit organization that offers pre-vocational (and new this summer, vocational) skills to kids with high-functioning autism and Asperger's syndrome. Her son Ian, now 17, was diagnosed autistic at the age of 2-1/2. "Our folks with Asperger's need services," she says. "They often pass because they're very bright and seem to be quite capable, and yet again and again we see our Asperger students fail at college, and employment. They may be able to do high math and physics but can't seem to get to work on time or self-motivate and take initiative in a way that makes them a productive employee."

Lawson's concern about the change in the DSM classification is that it could allow for a re-prioritizing of funds from regional centers that are in charge of allotting funds to schools. "I can imagine a re-defining of funding where they may look into it and say 'we're only going to fund those people with lower I.Q.s.' Well, high-functioning individuals with Asperger's often have high I.Q.s."

Courtenay Bell is the creative director of Autistry, a special education teacher and a self-identified Aspie. She says there is some comfort in the label. "Growing up many of us were called things like spaz, freak, bookworm, etc., and when I was diagnosed as having Asperger's I was relieved and happy to have a community of people like me."

Bell points out that one in 88 children is now being diagnosed with an autism spectrum disorder every year. The high-functioning kids need vastly different educational support that many lament is hard

to find within the public school system. Bell is grateful to have been able to attend private schools most of her life.

Asperger's syndrome is not typically funded in the public schools in any special way. Parents can co-create Individualized Education Programs, or IEPs, for their kids, but overwhelmed and often inexperienced teachers don't always have the ability to accommodate these plans. Marin has several private schools that are geared directly to the autism population, including Oak Hill in San Anselmo, Star Academy and Anova in San Rafael.

Oak Hill School, started 11 years ago by four families with autistic children, is an "NPS" or non-public school designated to receive students the public schools can't educate, with tuition paid by the school district. The families' shared therapist, Barbara Kalmanson, of Kentfield, a clinical psychologist and 40-year veteran in special education, helped advise them.

Kalmanson emphasizes that there is no "one size fits all" approach to helping children with autism spectrum disorders; educational programs must be tailored to meet the children where they are. Because of the need for such specialized education, there are many who fear lumping Asperger's into autism spectrum disorder with no distinction in functionality has the potential to place those higher functioning kids into "catchall" classrooms where they will fail.

"[Asperger's and autistic] brains work differently," says Susan Andrews, executive director of Oak Hill School. "In an ideal world, children on the spectrum benefit best from a tailored environment, at least in the early years."

At Anova School's San Rafael campus of 60 students with developmental disorders, about half are diagnosed with Asperger's. Executive Director Andrew Bailey isn't worried about the proposed change in labeling of Asperger's because it doesn't factor into the school's educational strategies.

"I don't think the labels are particularly helpful for anybody except for those people

who are on the spectrum and want to understand themselves better. Just like with a cold, you look at the symptoms—so with autism we treat symptoms."

Of course, helping people with Asperger's doesn't end at school. With their high I.Q.s and ability to hyper-focus, they seem like perfect candidates for college and employment, but they often wind up failing there as well.

"Where they need help is with executive functioning: planning of a task, organizing of a task—you can see in terms of employment how important that is," says Andrews.

The folks at Autistry Studios understand that what is often labeled a weakness in school or life is actually a strength. Says Lawson, "These are the kids that you grew up with who knew everything about dinosaurs or solar systems or trains. In fact," she says with a chuckle, "If you have a significant interest in trains, I can almost guarantee you're on the spectrum."

Courtenay Bell attributes strong memory recall, information retention and critical thinking to her Asperger's.

Within their area of interest, Aspies (and autistics) "hyper-focus" and become very dedicated. The idea, then, is to meet them where they are and slowly expand their thinking.

"If they are into trains, we build trains," says Lawson. "Then we'll say, 'Tanks have a lot in common with trains,' and we walk slowly to enlarge their world."

Autistry is also expanding, thanks to a grant from the Bothin Foundation of \$36,500, into on-the-job training, starting "Autistry Enterprises." Here, students will take their own ideas from concept to product—they will design, make and market their products, providing them valuable practical skills they can take out into the world.

"We start by listening to them and responding to their particular needs and building a program around that," says Lawson.

For parents who can't take advantage of private programs, advocacy in the schools is important. For Aspies themselves to succeed better, Lawson suggests, "they need to teach others how to communicate with them." **

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