

Newsletter February 2012

Hello Evanston CASE members!

There are some terrific articles in this month's newsletter that I think you will find inspirational and informative. "I Had Asperger's...Briefly," is written by a man who shares his story about the complexities involved in diagnosing people on the high functioning autism spectrum. Click on the links at the end of the article to learn about the impact of the coming changes in the definition of autism in the DSM-V, which is used by doctors, insurance companies and educators to determine whether a child meets the criterion for an autism spectrum disorder.

Also, read an inspiring story, "Wonder Dog", about the way a specially-trained service dog changed the life of a boy with neurological impairments from Fetal Alcohol Syndrome. There is also a link on the article for a short video showing the process involved in training these exceptional animals for the specific needs of the child.

I have included information about a workshop entitled **Parenting in SPACE 2012**, which is being offered by House Calls Counseling on the topic of Therapeutic Parenting. To see a fantastic video example of therapeutic parenting showing what to do when your child is locked in a power struggle with you, visit **Evanston CASE on Facebook** and click on the link. It will open your eyes!

**Some exciting developments are on the horizon for CASE!** We are applying for non-profit status and hope to have that in place by next month. This will allow us to fundraise more substantially and give us the opportunity to increase our impact in the community. Our new website will launch next month and our newsletter will have a new look in March. Stay tuned...

**IEP Annual Review season** is just around the corner. If you have any concerns about this process, please call us. We can help.

Warm regards,

Cari Levin, LCSW Founding Director Evanston CASE

**REMINDER: Parent Connections** this Thursday, February 16<sup>th</sup>

The Parent Connections meeting will be held on Thursday, February 16<sup>th</sup> from 7-9 p.m. at Boocoo Café, 1823 Church Street. The topic this month is: **Teaching Children Social Skills: What can parents do at home?** We are excited to have two presenters, Dr. Miri Arie and Ms. Chava Alpert, MSW, LCSW, who are the co-directors of **Social Endeavors** in Evanston. For more information about the services they offer at Social Endeavors, visit their website at <a href="https://www.socialendeavors.net">www.socialendeavors.net</a>. Please contact us if you plan to attend – (847) 556-8676 or info@evanstoncase.org.

# Therapeutic Parenting Workshop Offered by House Calls Counseling

"<u>Parenting in SPACE 2012</u>", is a conference for parents who want to learn the foundations of therapeutic parenting. It will be held April 21 & 22, 2012 at the lovely Morton Arboretum in Lisle, Illinois. It is sponsored by <u>House Calls Counseling</u>. Here are some quotes from parents who attended the conference last year:

"I realized, [from the conference] how [my children's] experiences have truly shaped them and that healing takes time." I was reminded of "how our children process things, how very much they need understanding and empathy," that I need to "...have more patience for them when they are speaking in behaviors" and to be more "accepting and compassionate towards our kids feelings."

And though I "still get frustrated with them," "I [now] have a greater degree of empathy for what they have experienced in their short lives and how damaging this has been for them. I don't feel hopeless about their future and their ability to heal." Because of this, "I am calmer, more patient, more willing to explore looking at things from different angles." In the end, "the sense of community and connectedness that arose out of it was landmark to me... transformational and totally unexpected."

If you know of parents/families that would benefit from attending this year's conference, please forward this "tale" to them or let them know about. Please: pass along the healing of Parenting in SPACE to those who need it most! Go to <a href="http://www.HouseCallsCounseling.com">http://www.HouseCallsCounseling.com</a> for more information and registration. <a href="Parenting in SPACE 2012">Parenting in SPACE 2012</a>, a conference for parents who want to learn the foundations of therapeutic parenting, will be held April 21 & 22, 2012 at the lovely Morton Arboretum in Lisle, Illinois. It is sponsored by <a href="House Calls Counseling">House Calls Counseling</a>.

This article was printed in the Opinion Pages of the New York Times on January 31, 2012. With the proposed changes to the DSM V – the newest version of the Diagnostic and Statistical Manual – information about how the autism spectrum will be defined could have significant implications on insurance coverage and educational services. There are links to related articles at the end.

#### "I Had Asperger Syndrome. Briefly."

#### **By BENJAMIN NUGENT**

Manchester, N.H.

FOR a brief, heady period in the history of autism spectrum diagnosis, in the late '90s, I had Asperger Syndrome.

There's an educational video from that time, called "Understanding Asperger's," in which I appear. I am the affected 20-year-old in the wannabe-hipster vintage polo shirt talking about how keen his understanding of literature is and how misunderstood he was in fifth grade. The film was a research project directed by my mother, a psychology professor and Asperger specialist, and another expert in her department. It presents me as a young man living a full, meaningful life, despite his mental abnormality.

"Understanding Asperger's" was no act of fraud. Both my mother and her colleague believed I met the diagnostic criteria laid out in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. The manual, still the authoritative text for American therapists, hospitals and insurers, listed the symptoms exhibited by people with Asperger disorder, and, when I was 17, I was judged to fit the bill.

I exhibited a "qualified impairment in social interaction," specifically "failure to develop peer relationships appropriate to developmental level" (I had few friends) and a "lack of spontaneous seeking to share enjoyment, interests, or achievements with other people" (I spent a lot of time by myself in my room reading novels and listening to music, and when I did hang out with other kids I often tried to speak like an E. M. Forster narrator, annoying them). I exhibited an "encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus" (I memorized poems and spent a lot of time playing the guitar and writing terrible poems and novels).

The general idea with a psychological diagnosis is that it applies when the tendencies involved inhibit a person's ability to experience a happy, normal life. And in my case, the tendencies seemed to do just that. My high school G.P.A. would have been higher if I had been less intensely focused on books and music. If I had been well-rounded

enough to attain basic competence at a few sports, I wouldn't have provoked rage and contempt in other kids during gym and recess.

The thing is, after college I moved to New York City and became a writer and met some people who shared my obsessions, and I ditched the Forsterian narrator thing, and then I wasn't that awkward or isolated anymore. According to the diagnostic manual, Asperger syndrome is "a continuous and lifelong disorder," but my symptoms had vanished.

Last year I sold a novel of the psychological-realism variety, which means that my job became to intuit the unverbalized meanings of social interactions and create fictional social encounters with interesting secret subtexts. By contrast, people with Asperger syndrome and other autism spectrum disorders usually struggle to pick up nonverbal social cues. They often prefer the kind of thinking involved in chess and math, activities at which I am almost as inept as I am at soccer.

The biggest single problem with the diagnostic criteria applied to me is this: You can be highly perceptive with regard to social interaction, as a child or adolescent, and still be a spectacular social failure. This is particularly true if you're bad at sports or nervous or weird-looking.

As I came into my adult personality, it became clear to me and my mother that I didn't have Asperger syndrome, and she apologized profusely for putting me in the video. For a long time, I sulked in her presence. I yelled at her sometimes, I am ashamed to report. And then I forgave her, after about seven years. Because my mother's intentions were always noble. She wanted to educate parents and counselors about the disorder. She wanted to erase its stigma.

I wonder: If I had been born five years later and given the diagnosis at the more impressionable age of 12, what would have happened? I might never have tried to write about social interaction, having been told that I was hardwired to find social interaction baffling.

The authors of the next edition of the diagnostic manual, the DSM-V, are considering a narrower definition of the autism spectrum. This may reverse the drastic increase in Asperger diagnoses that has taken place over the last 10 to 15 years. Many prominent psychologists have reacted to this news with dismay. They protest that children and teenagers on the mild side of the autism spectrum will be denied the services they need if they're unable to meet the new, more exclusive criteria.

But my experience can't be unique. Under the rules in place today, any nerd, any withdrawn, bookish kid, can have Asperger syndrome.

The definition should be narrowed. I don't want a kid with mild autism to go untreated. But I don't want a school psychologist to give a clumsy, lonely teenager a description of his mind that isn't true.

Benjamin Nugent, the director of creative writing at Southern New Hampshire University, is the author of "American Nerd: The Story of My People."

### Related News

New Definition of Autism Will Exclude Many, Study Suggests (January 20, 2012)

#### Related in Opinion

Op-Ed Contributor: Asperger's History of Over-Diagnosis (February 1, 2012)

Read this moving and inspirational article from the New York Times Magazine on February 2, 2012. It's about the impact of a specially trained therapy dog on a child who has explosive behavior due to the neurological effects of Fetal Alcohol Syndrome.

## **Wonder Dog**

By MELISSA FAY GREENE

In May 1999, Donnie Kanter Winokur, 43, a writer and multimedia producer, and her husband, Rabbi Harvey Winokur, 49, beheld the son of their dreams, the child infertility denied them. Andrey, a pale dark-eyed 1-year-old in a cotton onesie, held in a standing position by a caregiver, appeared in a short videotape recorded in a Russian

orphanage. If the couple liked the little boy, they could begin the legal process of adopting him. They liked the little boy very much.

Four months later, the Winokurs flew to Russia from their home in Atlanta to adopt Andrey, whom they renamed Iyal, and to adopt an unrelated little girl two days younger, whom they named Morasha. All four appear in another orphanage video: the beaming new parents on the happiest day of their lives, the toddlers passive in the arms of the strangers cradling and kissing them. In August 1999, the family arrived home to congratulations, gifts and helium balloons.

"Sometime after their 3rd birthdays, our wonderful fairy tale of adopting two Russian babies began to show cracks," said Donnie Winokur, who is now 55. She is pert and trim, with cropped brown hair and a pursed-lips, lemony expression softened by wearying experience. Unlike bright and cheery Morasha, Iyal grew oppositional and explosive. He was a sturdy, big-hearted boy with a wide and open face, shiny black hair in a bowl cut and a winning giggle. But, triggered by the sight of a cartoon image on a plastic cup, or an encounter with Morasha's Barbie dolls, he threw tantrums that shook the house. He stuffed himself at mealtimes with an inexplicable urgency. In a fast-moving car, he unfastened his seat belt and tried to jump out. He awoke every night in a rage. "I had panic attacks in the night when I heard him coming," she said. "I assumed everything was my fault, that I was not a good-enough mother." To read the rest of the article, click here: <a href="http://www.nytimes.com/2012/02/05/magazine/wonder-dog.html? r=1&pagewanted=all">http://www.nytimes.com/2012/02/05/magazine/wonder-dog.html? r=1&pagewanted=all</a>. There is also a link in the article to a video about the training process at 4 Paws for Ability.