



UPI ASKS, "WHERE'S ALL THE AUTISTIC AMISH?"

In a two-part series, United Press International Investigative Reporter Dan Olmsted explores the assertion that autism is genetic by studying one of the few remaining communities in the United States that does not routinely vaccinate their children: The Amish. His story appears below.

United Press International

April 18-19, 2005

The Age of Autism: The Amish anomaly

By Dan Olmsted

UNITED PRESS INTERNATIONAL

Lancaster, PA, Apr. 18 (UPI) -- Part 1 of 2. Where are the autistic Amish? Here in Lancaster County, heart of Pennsylvania Dutch country, there should be well over 100 with some form of the disorder.

I have come here to find them, but so far my mission has failed, and the very few I have identified raise some very interesting questions about some widely held views on autism.

The mainstream scientific consensus says autism is a complex genetic disorder, one that has been around for millennia at roughly the same prevalence. That prevalence is now considered to be 1 in every 166 children born in the United States.

Applying that model to Lancaster County, there ought to be 130 Amish men, women and children here with Autism Spectrum Disorder.

Well over 100, in rough terms.

Typically, half would harbor milder variants such as Asperger's Disorder or the catch-all Pervasive Development Disorder, Not Otherwise Specified -- PDD-NOS for short.

So let's drop those from our calculation, even though "mild" is a relative term when it comes to autism.

That means upwards of 50 Amish people of all ages should be living in Lancaster County with full-syndrome autism, the "classic autism" first described in 1943 by child psychiatrist Leo Kanner at Johns Hopkins University. The full-syndrome disorder is hard to miss, characterized by "markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activities and interests," according to the Diagnostic and Statistical Manual of Mental Disorders.

Why bother looking for them among the Amish? Because they could hold clues to the cause of autism.

The first half-dozen articles in this ongoing series on the roots and rise of autism examined the initial studies and early accounts of the disorder, first identified by Kanner among 11 U.S. children born starting in 1931.

Kanner wrote that his 1938 encounter with a child from Mississippi, identified as Donald T., "made me aware of a behavior pattern not known to me or anyone else theretofore." Kanner literally wrote the book on "Child Psychiatry," published in 1934.

If Kanner was correct -- if autism was new and increasingly prevalent -- something must have happened in the 1930s to trigger those first autistic cases. Genetic disorders do not begin suddenly or increase dramatically in prevalence in a short period of time.

That is why it is worth looking for autistic Amish -- to test reasoning against reality. Largely cut off for hundreds of years from American culture and scientific progress, the Amish might have had less exposure to some new factor triggering autism in the rest of population.

Surprising, but no one seems to have looked.

Of course, the Amish world is insular by nature; finding a small subset of Amish is a challenge by definition. Many Amish, particularly Old Order, ride horse-and-buggies, eschew electricity, do not attend public school, will not pose for pictures and do not chat casually with the "English," as they warily call the non-Amish.

Still, some Amish today interact with the outside world in many ways. Some drive, use phones, see doctors and send out Christmas cards with family photos. They all still refer to themselves as "Plain," but the definition of that word varies quite a bit.

So far, from sources inside and outside the Amish community, I have identified three Amish residents of Lancaster County who apparently have full-syndrome autism, all of them children.

A local woman told me there is one classroom with about 30 "special-needs" Amish children. In that classroom, there is one autistic Amish child.

Another autistic Amish child does not go to school.

The third is that woman's pre-school-age daughter.

If there were more, she said, she would know it.

What I learned about those children is the subject of the next column.

The Age of Autism: Julia

By Dan Olmsted

UNITED PRESS INTERNATIONAL

Leola, PA, Apr. 19 (UPI) -- Part 2 of 2. Three-year old Julia is napping when I arrive at the spare, neat, cheerful house on Musser School Road near the town of Leola in Lancaster County.

She is the reason I have driven through the budding countryside on this perfect spring day, but I really do not need to meet her.

In the last column, I wrote about trying to find autistic Amish people here in the heart of Pennsylvania Dutch country, and noted there should be dozens of them -- if autism occurs at the same prevalence as the rest of the United States.

So far, there is evidence of only three, all of them children, the oldest age 9 or 10. Julia is one of them. I found out about her through a pediatrician in Richmond, Va., Dr. Mary

Megson. I had been asking around for quite some time about autism and the Amish, and she provided the first direct link.

Megson said she would give my name to this child's mother, who could call if she chose. A few days later the phone rang. It was Stacey-jean Inion, an Amish-Mennonite woman. She, her husband Brent and their four children live simply, but they do drive a vehicle and have a telephone. After a few pleasantries, I told her about my trying to find autistic Amish.

Here is what she said, verbatim:

"Unfortunately our autistic daughter -- who's doing very well, she's been diagnosed with very, very severe autism -- is adopted from China, and so she would have had all her vaccines in China before we got her, and then she had most of her vaccines given to her in the United States before we got her.

"So we're probably not the pure case you're looking for."

Maybe not, but it was stunning that Julia Inion, the first autistic Amish person I could find, turned out to be adopted -- from another country, no less. It also was surprising that Stacey-jean launched unbidden into vaccines, because the Amish have a religious exemption from vaccination and presumably would not have given it much thought.

She said a minority of Amish families do, in fact, vaccinate their children these days, partly at the urging of public health officials.

"Almost every Amish family I know has had somebody from the health department knock on our door and try to convince us to get vaccines for our children," she said. "The younger Amish more and more are getting vaccines. It's a minority of children who vaccinate, but that is changing now."

Did she know of any other autistic Amish? Two more children, she said.

"One of them, we're very certain it was a vaccine reaction, even though the government would not agree with that."

Federal health officials have said there is no association between vaccinations and autism or learning disabilities.

"The other one I'm not sure if this child was vaccinated or not," she added.

During my visit to their home, I asked Stacey-jean to explain why she attributed the first case to vaccines.

"There's one family that we know, their daughter had a vaccine reaction and is now autistic. She was walking and functioning and a happy bright child, and 24 hours after she had her vaccine, her legs went limp and she had a typical high-pitched scream. They called the doctor and the doctor said it was fine -- a lot of high-pitched screaming goes along with it.

"She completely quit speaking," Stacey-jean said. "She completely quit making eye contact with people. She went in her own world."

This happened, Stacey-jean said, at "something like 15 months." The child is now about 8.

For similar reasons, Julia Inion's Chinese background is intriguing. China, India and Indonesia are among countries moving quickly to mass-vaccination programs. In some vaccines, they use a mercury-based preservative called thimerosal that keeps multiple-dose vials from becoming contaminated by repeated needle sticks.

Thimerosal was phased out of U.S. vaccines starting in 1999, after health officials became concerned about the amount of mercury infants and children were receiving. The officials said they simply were erring on the side of caution, and that all evidence favors rejection of any link between Autism Spectrum Disorders and thimerosal, or vaccines themselves.

Julia's vaccinations in China -- all given in one day at about age 15 months -- may well have contained thimerosal; the United States had stopped using it by the time she was born, but other countries with millions to vaccinate had not.

Stacey-jean said photographs of Julia taken in China before she was vaccinated showed a smiling alert child looking squarely at the camera. Her original adoptive family in the United States, overwhelmed trying to cope with an autistic child, gave Julia up for re-adoption. The Inions took her in knowing her diagnosis of severe autism.

I tried hard -- and am still trying -- to find people who know about other autistic Amish. Of the local health and social service agency personnel in Lancaster, some said they dealt

with Amish people with disabilities, such as mental retardation, but none recalled seeing an autistic Amish.

Still, I could be trapped in a feedback loop: The Amish I am likeliest to know about -- because they have the most contact with the outside world -- also are likeliest to adopt a special-needs child such as Julia from outside the community, and likeliest to have their children vaccinated.

Another qualifier: The Inions are converts to the Amish-Mennonite religion (Brent is an Asian-American). They simply might not know about any number of autistic Amish sheltered quietly with their families for decades.

It also is possible the isolated Amish gene pool might confer some kind of immunity to autism -- which might be a useful topic for research.

Whatever the case, Stacey-jean thinks the autistic Amish are nowhere to be found.

"It is so much more rare among our people," she said. "My husband just said last week that so far we've never met a family that lives a healthy lifestyle and does not vaccinate their children that has an autistic child. We haven't come across one yet."

"Everywhere I go (outside the Amish community) I find children who are autistic, just because I have an autistic daughter -- in the grocery store, in the park, wherever I go. In the Amish community, I simply don't find that."

--

UPI researcher Kyle Pearson contributed to this article.