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The Age of Autism: Oaklawn

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Washington, DC, May. 26 (UPI) -- Finally. I found a place that could tell me all about Amish people with autism.

"I talked to the people who work with the Amish program specifically, because they have more familiarity with the Amish families, and they said, oh yeah, definitely, they have seen autism in Amish families," said Gloria Holub, a staff member at Oaklawn Psychiatric Center in Goshen, Ind. The center treats people with mental health problems, including autism.

"We started our Amish program four or five years ago. We've always had some Amish patients but they were just integrated into the regular treatment program," she told me. But they were "uncomfortable in a unit with television on in a therapy group with 'English'" as the Amish call the rest of us.

Working with Amish bishops in the area around Goshen, Oaklawn helped create a first-of-its-kind residential facility that uses the center's therapists. It does "quite a large business," Holub said, and draws Amish from all over including Pennsylvania and Ohio, the two largest populations. One therapy group speaks only Pennsylvania Dutch.

So far in my search for autism among the Amish, I'd found three or possibly four cases in Lancaster County, Pa. In addition, a pediatrician in Virginia Beach, Va., told me he was treating six -- three from Pennsylvania, two from Ohio and one from Texas. With a population approaching 100,000 nationwide, and a national autism rate of 1 in 166 children, there should be several hundred more.

They seem few and far between, however, and people who should know -- an Amish-Mennonite mother with an autistic daughter adopted from China, a pediatric hospital nurse in Pennsylvania Dutch country, a doctor who has treated thousands of Amish for nearly 25 years -- told me they were struck by the seeming low prevalence. Intriguingly, four of the Virginia doctor's cases and at least two of those in Lancaster County share a possible link to mercury, the two in Lancaster by way of vaccinations and the others through what the doctor said were very high mercury levels.

Few Amish vaccinate their children, which is what led me to explore their world in the first place. Some parents of autistic children and a small minority of doctors and scientists assert that mercury in vaccines and the environment triggered a sharp rise in autism cases in the 1990s. Most mainstream experts and public health officials reject that theory as totally discredited. Thimerosal, the mercury-based vaccine preservative, was phased out in the United States beginning in 1999.

Finding the autism rate in an unvaccinated population might help settle the issue, and it was a logical progression in the series I've been doing about the natural history of the disorder. The first surprise was that no one seems to have looked.

Just because autistic Amish are hard to find doesn't mean they aren't there, of course, especially given the insular nature of the Amish community. A number of readers have reminded me of that fact. Some argue that the Amish might have a genetic immunity to the ailment.

Now, it seemed, I had come to the right place to get some answers.

"I asked the two people who work with that program and they both definitely have seen autism in the Amish community in kids," Holub told me. I asked her if I could talk to one of the therapists, and she put a friendly man named Dale Raber on the phone.

"I've been trying to find out whether there is autism in the Amish community," I explained, "and I haven't found much of it, and I understand you're aware of some folks in the Amish community with autism?"

"We have a specific Amish program more with adults with schizophrenia, bipolar, depression, some of the more typical mental health issues, but, there are a number of, I mean I don't have a number of them here that I have personal experience with, but I think there are a number of cases of autism among the Amish."

"You're familiar with, like, actual specific cases?" I asked.

"I haven't, I've had one actual client here who was diagnosed with Asperger's, which is in the autism family," Raber said. "And that person wasn't actually Amish -- our Amish program also serves what you would call 'horse-and-buggy Mennonites.'"

"I would think there would have to be autism among the Amish, just because it's among the rest of the population," Raber said. He added that because autistic kids tend to have problems once they get to school, they might end up using developmental disability agencies as opposed to a mental health center like Oaklawn.

"So that would be my guess why we don't see a lot of it. I would think that it probably happens among the Amish. I don't have any evidence to back this up, but I would guess it's about the same it is in the general population."

Raber remarked that the Asperger's case was surprising to see among the horse-and-buggy Mennonites - that he was more familiar with it as a "West Coast" phenomenon. Several national stories have highlighted the rate of Asperger's Disorder in California, particularly in the high-tech Silicon Valley south of San Francisco.

I told Raber that I was trying to test the idea that the Amish, due to a low rate of vaccination or low exposure to some other possible culprit, might hold clues to autism.

"Ohhhh.....," he responded, sounding surprised and intrigued. I asked if the horse-and-buggy Mennonites vaccinated their children. He consulted with a colleague in the office at the time and decided they probably did.

You can see why people conclude there are about the right number of Amish with autism -- there should be, and it's certainly everywhere else. You see lots of Amish, and you see lots of people with autism, and you put them together. Even the doctor in Lancaster County never thought about it till I asked him, and he has seen thousands of Amish patients over 25 years -- not one, he suddenly realized, with autism.

Looking for them is starting to seem like watching smoke from a roadside brushfire drift slowly out of sight.

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This ongoing series on the roots and rise of autism aims to be interactive with readers and will take note of comment, criticism and suggestions. E-mail: dolmsted@upi.com