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The Age of Autism: Absence of evidence

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Lebanon, PA, May. 9 (UPI) -- After several weeks of looking, the prevalence of autism among the central Pennsylvania Amish still appears remarkably low, and the few cases I have found suggest an ominous pattern.

In two columns last month I asked, "Where are the autistic Amish?"

My search encompassed Lancaster County, heart of Pennsylvania Dutch country, and I obtained a tentative answer. After inquiring widely, these three cases emerged:

--a girl, age 3, adopted from China by an Amish-Mennonite family;

--a girl of about 8, described by the mother of the first child as a clear vaccine reaction at 15 months (a very small percentage of Amish do vaccinate their children), and

--a boy of about 10.

Since then, I have become aware of possibly one more case in Lancaster County and a total of five more nationwide -- which will be the subject of a future column.

Meanwhile, there is the question of prevalence. There is no reason to be particularly interested in autism among the Amish -- unless it occurs much less frequently than normal. If it did, it would suggest either genetic immunity -- which is unlikely, because at least a handful of Amish are in fact autistic -- or lower exposure to something that, combined with genetic susceptibility, triggers autism.

In my view, the latter is more likely.

About 22,000 Amish live in Lancaster County, where they first put down roots almost 300 years ago after fleeing religious persecution in Germany. At the current rate of autism among the "English," as they call the rest of us, several dozen of them should be identifiably autistic.

My first Lancaster contacts basically fell into the "absence of evidence" category, which is intriguing, but establishes nothing. The well-known scientific axiom is, "absence of evidence is not evidence of absence."

In the absence-of-evidence category:

--"I've been an advocate for the past five years in Lancaster and I have yet to come across a case where an Amish family is struggling for services," said Jim Boudier of the Lancaster County Autism Support Group. "I haven't seen any."

--"There are a lot of other kids who have autism, but we haven't seen that in the Amish because they're not referring them," said Stu Symons, director of mental retardation and early intervention services for Lancaster County Mental Health/Mental Retardation, a public agency. "There's a lot of birth defects and other disabilities (among the Amish), but we haven't seen, necessarily, autism."

--"That's one of our head-scratchers," said another local person who works with autistic children.

The Amish-Mennonite mother with whom I spoke, Stacey-jean Inion of Leola, said the view from inside looking out is no different.

"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," Inion said. "In the Amish community, I simply don't find that."

Though all this seemed intriguing, it did not constitute proof of anything. Because of the insular and unusual nature of the Amish community, everyone outside might just be missing the necessary evidence.

Among the dozens of e-mail messages I read after publishing the previous articles, several made exactly that point.

"I do not know of any Amish or Mennonite children with autism," said one doctor in a neighboring county, "but it would be difficult to assess this because these families rarely come to medical care for that type of problem, nor do they use Early Intervention or IU (Intermediate Unit) services. Thus, the incidence of autism in that population is unknown."

One message board posting even suggested because there apparently have been no studies of Amish people with autism, they must be there.

"Proof? Evidence? Where is it written other than a newspaper article or forum message? A search for 'amish autism' on ncbi.nlm.nih.gov/entrez/query.fcgi?CMD=search&DB=pubmed only comes up with a 'No items found' message. You would think that anything that significant would actually be published."

You would think.

This past weekend, I traveled back to Pennsylvania and met with a person who gave me the best insights yet into autism in the Amish community here. What he had to say was the tipping point between absence-of-evidence and evidence-of-absence.

That will be the focus of the next column.

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