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An Outbreak of Autism, or a Statistical Fluke?

By DONALD G. McNEIL Jr.

MINNEAPOLIS — Ayub Abdi is a cute 5-year-old with a smile that might be called shy if not for the empty look in his eyes. He does not speak. When he was 2, he could say “Dad,” “Mom,” “give me” and “need water,” but he has lost all that.

He does scream and spit, and he moans a loud “Unnnnh! Unnnnh!” when he is unhappy. At night he pounds the walls for hours, which led to his family’s eviction from their last apartment.

As he is strapped into his seat in the bus that takes him to special education class, it is hard not to notice that there is only one other child inside, and he too is a son of Somali immigrants.

“I know 10 guys whose kids have autism,” said Ayub’s father, Abdirisak Jama, a 39-year-old security guard. “They are all looking for help.”

Autism is terrifying the community of Somali immigrants in Minneapolis, and some pediatricians and educators have joined parents in raising the alarm. But public health experts say it is hard to tell whether the apparent surge of cases is an actual outbreak, with a cause that can be addressed, or just a statistical fluke.

In an effort to find out, the Minnesota Department of Health is conducting an epidemiological survey in consultation with the federal Centers for Disease Control and Prevention. This kind of conundrum, experts say, arises whenever there is a cluster of noncontagious illnesses.

While there is little research on autism clusters, reports of cancer clusters are so common that health agencies across the country respond to more than 1,000 inquiries about suspected ones each year. A vast majority prove unfounded, and even when one is confirmed, the cause is seldom ascertained, as it was for Kaposi’s sarcoma among gay men and mesothelioma among asbestos workers.

It is “extraordinarily difficult” to separate chance clusters from those in which everyone was exposed to the same carcinogen, said Dr. Michael J. Thun, the American Cancer Society’s vice president for epidemiology.

Since the cause of autism is unknown, the authorities in Minnesota say it is hard to know even what to investigate.

“There are obviously some real concerns here, but we don’t want to make a cursory judgment,” said Buddy Ferguson, a health department spokesman. Even counting autism cases is difficult because the diagnoses are first made by the schools, not doctors, and population estimates for Somalis vary widely. Results are expected late this month.

Even if the department confirms that a cluster exists, it will not answer the question why. Still, Dr. Thun said a possible focus in one ethnic group “increases my sense that investigating it is essential.” The next step, he added, would be to look at Somalis in other cities.

A small recent study of refugees in schools in Stockholm found that Somalis were in classes for autistic children at three times the normal rate.

Calls to representatives of Somali groups in Seattle and San Diego found that they were aware of the fear in Minneapolis but unsure about their own rates. Doctors familiar with the Somali communities in Boston and Lewiston, Me., had heard of no surges there.

“It’s a concern here, but we haven’t done anything to look specifically,” said Ahmed Salim of Somali Family Services in San Diego.

Shamso Yusuf of the Refugee Women’s Alliance in Seattle said tearfully that her own daughter had been given a diagnosis of autism, “and I see a lot of parents who have 5-year-olds who cannot speak.” But no Seattle study has been done, she said.

Somalis began arriving in Minneapolis in 1993, driven out by civil war; now their population in Minnesota is estimated at 30,000 to 60,000. The city is welcoming and social benefits are generous, but many live a life apart as conservative Muslims, the women in head scarves and long dresses. Many Somali men have jobs as taxi drivers or security guards; others are accountants or run shops in the mini-malls catering to Somalis.

Antivaccine activists are campaigning among them, which worries public health officials, especially because some families go back and forth to Somalia, where measles is still a significant cause of childhood death, according to Unicef.

One of the first to raise the alarm was Anne Harrington, who worked in special education in the Minneapolis schools for 21 years.

In the last decade, she said, “we’ve begun seeing a tremendous number of kids born here who have the more severe forms of autism.”

Last year, she said, 25 percent of the children in preschool classes offering the most intensive treatment had Somali parents, while only about 6 percent of public school enrollment is Somali.

Dr. Daniel S. McLellan, a pediatrician, said that when he began practicing at Children’s Hospital six years ago, he was struck by how many autistic Somali children he saw.

“They had classic symptoms,” he said. “Really impaired language, didn’t watch faces, didn’t make eye contact, didn’t communicate with gestures, just lost in their own worlds. Nobody would mistake it for anything else.”

Speculation is rampant about possible causes: living conditions in Somalia or in refugee camps in Kenya; traditional medicines; intermarriage; genetic predisposition; vitamin D deficiencies due to a lack of sunlight; and, of course, vaccines.

But each theory has weaknesses.

Most of the children, said Idil Abdull, one of the first mothers of an autistic child to ask the authorities to investigate, were born here and have had the same medical care and shots as any child on Medicaid. It is not a case of misdiagnosis because of language problems; many have siblings doing well in school.

The Hmong, from Southeast Asia, who also immigrated here through refugee camps, do not have high autism rates, Ms. Harrington said.

Somali refugees have many illnesses, said Dr. Osman M. Ahmed of the East Africa Health Project in St. Paul, including tuberculosis, hepatitis B, depression from the civil war, and vitamin D deficiencies.

But lack of vitamin D is a dubious explanation. Rates of the disorder are similar among black and white Americans, according to the C.D.C., and Somalis, on average, are no darker-skinned than black Americans.

In Somalia, cousins do marry cousins. Globally, according to the March of Dimes, birth defect rates are highest in Arab countries with close intermarriage. But Somalia's birth defect rate is moderate, and autism is not part of such studies.

In any case, many Somali parents are baffled and scared.

"It's beyond denial," said Hassan Samantar, a parent advocate at the Pacer Center for disabled children. "There was no word for this in Somali. We've seen Down syndrome and schizophrenia, but loosely termed — our word is more like 'crazy.' People are calling it 'otismo' or 'the American disease.' And some are saying it's something you did or your parents did, and the curse is catching up with you."

Many Somali parents here do not read English or watch American television, he said, so they first hear of autism only when a pediatrician suggests testing a child.

Some send their children back to relatives in Somalia.

"They say, 'There's more sunshine, there's less pollution, the food is fresher because the animal was killed that morning,'" Ms. Abdull said. "They say: 'My kid won't talk? Throw him in the middle of 20 other kids, and he'll talk. They'll tease him till he has to.' You know the way kids run around in Africa? People are so isolated in their apartments here. They think maybe they'll snap out of it."

Antivaccine groups have noticed. In November, J. B. Handley, a founder of Generation Rescue, which advocates treating autistic children with wheat- and dairy-free diets, vitamins and chelation to remove mercury, wrote an open letter to "Courageous Somali Parents."

He warned them not to trust the state health department and suggested they slow down their children's shots and get exemptions to school vaccination requirements. He also offered to pay for some to attend an antivaccine conference.

The appeal has had an effect. Many parents, including Ayub's, now say that their children's autism began after seizures that started after they got shots.

"People in the Somali community have gravitated to that theory, and many are resisting immunization," Dr. McLellan said.

But there are also children like 8-year-old Shumsudin Warsame, who does not speak more than one word at a time, runs in circles and hurts himself jabbing pens into his face. He was born in Somalia, grew up in Egypt and arrived here six months ago. He started having seizures before he was a year old, his father, Abdiasis, said, long before he had any vaccinations.

To Mr. Warsame, finding something to blame is beside the point. He is a single parent, and he and Shumsudin were at a health center hoping to find a part-time home care aide.

"I have a friend from Somalia with three kids with autism, all born in Minnesota," Mr. Warsame said. "I need help; we all need help. I don't see a lot of people trying to help us. It's better than it was in Egypt or Somalia, but it's not what I expected."