

Minneapolis and the Somali Autism Riddle

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Tomorrow, a few hundred very concerned citizens of Minnesota will gather to discuss a baffling and heartbreaking riddle: Why is the reported rate of autism among children of Somali refugees so alarmingly high (now an estimated 1-in-28 schoolchildren)?

When I first heard about this phenomenon, which some Somalis call the "Minnesota Disease," my reporter's instinct told me it could be a very big story; that a key piece of the puzzle that is autism might well lie within the bloodstreams of these poor children of the Twin Cities - whose families had already suffered through so much.

If it can be demonstrated that US-born children of Somali refugees are more prone to autism than the other kids of Minneapolis - or Somalia - then it shouldn't take too long to discover what it is about them (their genes) that clashed so terribly with the way they were conceived and raised (their environment).

It won't explain every case of autism, of course, but it might open new doors of understanding and knowledge that can be applied to combating autism worldwide.

The daylong conference on Saturday is a tribute to progressive public health and a responsive local government (plans include Somali translators, Somali food, breaks to allow time for Islamic prayer, and child care). The meeting is sponsored by a variety of Somali, autism and other community groups, as well as several State and City agencies, including the Minnesota Department of Health.

"The Somali community expressed a need for information on autism, and our duty is to respond to that, to provide as much information as possible, and in a cultural context," said state health department spokesman Doug Schultz. "The concern in the community is real, and if they have the perception that there is a high rate, then we need to talk about that."

But is there really a "high rate?" A written survey I conducted with 25 refugee parents of autistic children certainly revealed their strong belief that there is - and nearly all of them suspect the vaccine program of their adoptive country.

In August, the online newspaper MinnPost first reported that 12 percent of kindergarten and pre-school children with autism in Minneapolis speak Somali at home, and more than 17 percent of the kids in the early childhood autism program are Somali speaking.

The Minneapolis Star tribune published other staggering figures: Among Somali students in the district, 3.6

percent had autism - a rate of 360-per-10,000, (or 1 in 28). The paper said this was about twice as high as the already burgeoning district average of some 180-per-100,000 kids (or 1 in 56), and more than five times the national rate of 66-per-10,000 (1 in 150).

Virtually all of the children of Somali refugees were born in the United States, and they appear to be among the most severely affected children with autism in the district: Last year, one-in-four children in the preschool class for the most severe cases was Somali.

Reports of elevated autism rates among children of immigrants are nothing new. A small study this year showed that Swedish-born children of Somali immigrants to that country were far more likely to have autism than the general population, (Somalis there call autism the "Swedish Disease"), and another small study in 1995 found an autism rate of 15% among children in one Swedish town born to mothers from Uganda - 200 times more than the national average.

Higher than normal autism rates among children of immigrants have also been reported in Ireland, the UK and several cities in North America, especially Montreal.

Meanwhile, none of the refugees that I surveyed had ever heard of autism back in Somalia, where there isn't even a name for the disorder. In fact, no one had ever seen nor heard of a single child who displayed any of the common symptoms of autism -- though a few did report knowing kids with speech delay that eventually resolved itself.

Not everyone is convinced that there is a problem, however.

"These reports are interesting and need further review, but you don't just take something off the news as facts," cautioned Judy Punyko, an epidemiologist for the state department of health. "We need to obtain the actual data and analyze it, so I am not sure there is much of a story here at this point."

Punyko has assembled a team of experts to determine if the Somali autism rates are in fact higher than average in Minneapolis, and she was expected to release at least preliminary results at Saturday's meeting.

But on November 12, Dr. Punyko sent me an email saying she is not able to present any results yet, "only study aim, objectives, and progress to date. I am still in the process of gathering existing data and this is taking a lot more time than I had anticipated," she wrote. "These data are tough to work with."

The delay will not be welcome news to any of the Somali parents I spoke with. They know that, without proof that their children are being afflicted more than others, officials will not intervene to investigate.

One mother (who asked not to be identified due to the tremendous stigma of autism among Somalis), first approached state and city officials in April of 2007, beseeching them to look into the apparent problem. It wasn't until local reporters started snooping around, the mother said, that government stepped up to respond.

The parent refugee-activists even secured a teleconference meeting with health staffers in the DC office of Minnesota Senator Norm Coleman. They told the Somalis that, if the prevalence was shown to be higher in their community, they would urge the CDC and other Federal agencies to "look under every rock" to find out why - including environmental factors like mercury, thimerosal and vaccines.

Many Somali parents began to suspect vaccines as a possible cause on their own, and well before they encountered any American media or autism groups who could put the idea in their head.

In fact, one of the most obvious "environmental" differences between Minnesota and Somalia is mass vaccination (another is sunlight, but more on that later).

There are an estimated 15,000-40,000 Somalis living in Minnesota, which has the largest Somali population outside of East Africa. Most fled during or after the 1993 phase of the bloody Civil War in that country. Many spent years in often wretched refugee camps in Kenya, waiting for a chance to emigrate to Europe and North America.

A lot of the refugees got their chance in 2000, which is when the majority of Somalis arrived in Minneapolis, hoping to finally build a new life in peace and dignity.

Along the way, vaccines became an almost routine part of their life: They were often given in the camps, they were sometimes given before leaving Africa, and they were almost always given in the first year of arrival in the US (which requires a series of 10 vaccinations for all refugees, including women of child bearing age - many of those vaccines contain thimerosal).

Once they arrived in Minnesota, most refugees were welcomed by a progressive "Blue" state with a good public health infrastructure and a bureaucracy ready and willing to help. Refugees were given about a year or so of free medical and dental care, and special effort was made to ensure full compliance with the childhood vaccine schedule (though many mothers failed to keep well-baby visits, requiring lots of "catch up" vaccinations when they did bring their children in to the pediatrician).

Of the 25 refugee mothers who answered the questionnaire, most were vaccinated in refugee camps, and all but two were fully vaccinated after arriving in the US. About a third reported receiving vaccines while pregnant or shortly before becoming pregnant.

When asked what they thought was causing autism in their community, 22 respondents said that vaccines were at least partly to blame, while two were unsure, and only one said vaccines were uninvolved.

Many parents told me the same story of regression I have heard a thousand times before.

"He met all the normal milestones until he hit 18 months," lamented Abdulkadir Khalif, speaking of his three-year-old son with autism. "He was a beautiful baby, running around, saying a few words, until about the winter of 2006, right when he got his MMR (measles-mumps-rubella) shot. He got sick and we went to the hospital, and he stopped talking immediately around that time."

"Do I know it was the vaccines?" Khalif asks. "All I know is he stopped talking right around the time of those shots."

Neither Khalif nor his wife (who was given a thimerosal-containing flu shot while pregnant, even though the label instructed the doctor to administer the shot during pregnancy, "only when medically necessary"), had ever heard of autism until the day their son was diagnosed.

Khalif says, it is "not possible" that autism could be this common in Somalia. "I've been living with it on a daily basis, with my own child. And I lived in Somalia and Kenya for a long time. If it was this common, we would have had a name for it, and we don't. That tells me it does not exist."

"And these symptoms? I had never seen anything like it before. We have names for mental retardation or Down syndrome. But the mannerisms, the loss of speech, the tantrums and violence and running out of the house that comes with autism - I think we would have noticed those things. But we've never seen them before in Somalia or Kenya."

Hodan Hassan, mother to four children including four-year-old Jenny, who has autism, said she had been "a little lax and lazy" with vaccinating her first two kids, "and the doctors got mad at me." With Jenny, she vowed to get all shots on time (and dutifully got the flu shot while pregnant). But there seemed to be a problem with the record keeping, because Jenny was clearly over-vaccinated (for example, she received five Hepatitis B shots, when only three are required).

Soon after giving birth, Hassan started work at a hospital, where she received several mercury containing vaccines, even while breast feeding Jenny.

Jenny had several terrible, feverish reactions to some of her vaccines, twice requiring visits to the ER, where she was given IV fluids and Tylenol.

On Valentines Day, 2006, Hassan brought Jenny in for her 18-month well baby visit, right on time. "she was saying 'mommy' and 'daddy' and 'juice' and 'go, go let's go!'" Hassan recalls. "She was a very happy and attentive baby. She would look at you when talked to her, she would come when you called.

Then Jenny got five vaccines at once (M-M-R, Prevnar and chicken pox) at the doctor visit. She spiked a fever and returned to the hospital. "She never spoke again," Hassan said. "It was all gone right after those shots. I know the doctors don't believe it. They think we must be crazy. But these are our kids, and we were there when everything happened to them. The doctors were not."

Many of the parents I spoke with said they plan to stand up and speak out at the meeting, where Khalif and Hassan are both scheduled panel members.

"I have gathered information on 149 Somali families in Minneapolis with autistic children, and I plan on asking the experts why it is so much," Hassan said.

But she doesn't expect a ready answer. "I think they will try to cover it up at the meeting, avoid the issue, and say 'It is not what you guys think, you can trust us, this is not what it is,'" she said. "But that is not acceptable. Word of mouth went out and people are panicking, and they don't know who to trust. One American doctor told me he will not vaccinate any of his own kids, but has to vaccinate all the others. You have no idea what kind of message that sends to our community."

Khalif also plans on posing tough questions.

"I am going to make all those education and health officials feel very guilty," he said. "Where did this come from? This is a disease that's been acquired by our kids here. In each and in every case, all the children, with one exception, that have been identified with autism were born in this country. I want them to tell me directly that the vaccines are safe. I want someone to stand up and say that. And then, I want to ask that same person two years down road the same thing, and see what the percentages are like."

Khalif also wants to propose "a rescheduling of the vaccines for our Somali children, because I think there is something in our immune system that cannot handle that number of vaccines at one time. The rate is so high, that something will be found in our genes or systems. Science now has a window to find out the actual cause, and therefore the remedy, for autism."

Some doctors and researchers in Minneapolis that I spoke with were extraordinarily sympathetic toward the Somalis. "Vaccines have to be playing a role," said one very prominent pediatrician and researcher, who is working quietly behind the scenes to change attitudes at the University of Minnesota and elsewhere, and did not want to be named.

"Maybe if we start talking about the individual toxins in vaccines, and not the vaccine program as a whole, others in the medical profession will find it easier to come around," the doctor said.

Another local doctor, who did speak on the record, was willing to speculate on one possible variable that might make Somali kids more prone to autistic regression - with or without vaccines: Vitamin D deficiency.

Dr. Gregory A. Plotnikoff, medical director for the Institute for Health and Healing at Abbott Northwestern Hospital, said a colleague had noticed an "exceedingly high" rate of morning sickness among pregnant Somali women in Minneapolis, often requiring hospitalizations.

The doctor began checking Vitamin D levels and found that, on average, they were far below what is considered to be normal and healthy.

Somalis, he said, may start out with naturally low abilities to produce vitamin D from sunlight, (as is the case with many people with Middle Eastern blood in them). That is compounded by the fact that dark-skinned people require far more sunlight to produce vitamin D than light-skinned people and, when Somalis move to areas of higher latitude, with far less sunlight - their vitamin D stores may be virtually depleted, at least for part of the year.

"Vitamin D is crucial for normal brain development, because there are receptors for it throughout the brain," Plotnikoff said. "Vitamin D also plays a role as an anti-inflammatory agent and, besides cutting down on inflammation, it increases concentrations of glutathione, which better supports the brain's capacity to handle heavy metals and oxidative stress."

Glutathione has been found to be low or depleted in many children with autism. A lack of glutathione would make children more vulnerable to the effects of mercury and other heavy metals.

"Another problem is that Tylenol depletes glutathione, and regretfully, most kids who get a shot also get Tylenol," Plotnikoff said. "It's routinely given without considering that it can increase the risk of heavy metals, like mercury, causing oxidative injury in the brain."

"Glutathione has antioxidant properties, and it also chelates, or removes heavy metals in the body. We want a lot of it around. We need it, and we depend upon it," he added.

So, could there be a possible connection between vitamin D deficiency, glutathione depletion, heavy metal accumulation and autism?

"It's a hypothesis that absolutely needs to be tested," Plotnikoff said. "Vitamin D deficiency is crucial to study, because of its many roles in normal brain development -- including the capacity to handle oxidative stress and handle heavy metal loads. The data we have now can't say if this is the case, but it is a compelling hypothesis that deserves national attention."

"My sense is that autism is likely to be a result of a combination of many important factors," he continued. "The gift that the Somali community is giving us is about a significant awareness of the role of low vitamin D levels and other environmental issues, including immunizations and heavy metals, in autism. Severe Vitamin D deficiency could be what is behind all this. And that is what the Somali community did for us: They get no sun in Minnesota, and they have extremely low levels of vitamin D."

Finally, vitamin D deficiency in pregnant animals can lead to "dramatic" defects in mitochondrial function in offspring, according to at least one study. The role of mitochondrial dysfunction and autistic regression is only now beginning to be explored. But some researchers believe that poor mitochondrial health (perhaps exacerbated by vitamin D deficiency?) is a precursor to autistic regression in at least one subgroup of children.

All of this, of course, is speculation. There is no proof that any Somali autism cases were caused by vitamin D deficiency, lack of sunlight, mercury or vaccines. But if you look for major differences between life in Somalia and life in Minnesota, you will find that one has lots of sunlight and very few vaccines -- and the other has less sunlight, but lots of vaccines.

Is it possible that vitamin D deficiency caused glutathione depletion and mitochondrial damage to these Somali children, setting them up for regression into autism after receiving multiple simultaneous vaccines containing heavy metals (as was the case in the famous Hannah Poling Vaccine Court claim)?

No one knows. And sadly, some refugees are not waiting around for US doctors to find out.

"Some autism families have returned to Somalia," said one mother, who did not want to be identified. "They were angry and disgusted with the United States. The nation that offered them refuge was the same nation that made their children so sick," she said.

"They think that, by returning home, maybe they can make their children better."