

Best of A of A: Part 2, What Did the CDC Know and When Did They Know It?



Managing Editor's Note: We've re-run this post as a follow up to the resignation of Dr. Julie Gerberding.

Part 2 of 2

By Mark Blaxill

From the start of their activities in the Brick Township New Jersey autism study, the CDC's approach had been nothing short of diligent and competent. They responded rapidly to an expression of community concern and fielded a team that began what seemed to be all the right kind of work on the ground. The team generated a response within weeks of mobilizing. They held a press conference to express their support for community concerns about elevated autism rates. If not a virtuoso performance, it was certainly professional.

Then something changed. After their January 1999 press conference, the CDC team went underground.

After many months of active communication and prompt response, they ceased all communication with Bobbie Gallagher and other member of the Brick POSSE that had first noticed the surprisingly high number of autism cases in 3-4 year olds in Brick. Team members explained that higher-ups were concerned about the way the team had communicated their findings publicly, using the terms "elevated" and "cluster" in describing the autism situation. Vague political rumors circulated as an explanation for the new sensitivity from Washington DC. But whatever the cause, it wasn't until well over a year later, April 2000, that the CDC's Brick study team would resurface. And when they did, all talk of a cluster was gone. All concern expressed in mid 1997 for the surge in 3-4 year old kids (who were 4-6 years old in 1998) was gone as well. Politics and public relations priorities, it seems, had taken precedence.

There was, to be sure, more work to be done after January 1999. The team added more autism cases to its count of "over 40" reported in their first press conference. By the time of their final report in April 2000, the CDC had identified 60 cases of autism spectrum disorder (ASD) in a population of just 8,900 children between the ages of three and ten. This rate, 1 in 150 children, was the highest autism rate ever reported anywhere in the world up to that time, and might even have understated the real rate. Bobbie Gallagher believed the CDC's count left out quite a few families that had left Brick and that an approach that accounted for migration would have yielded over 70 cases.

But by early 1999, the CDC team had virtually all the information it would ever get on autism rates in Brick. What did they do with that information?

They had two questions they really needed to address in any final report. The first was the issue of locally elevated environmental toxins: the kind of industrial contamination that might have provoked a Brick autism cluster. The Brick POSSE certainly believed that they had discovered a cluster. Bobbie Gallagher thought that there was something in the water. And so there was great concern over specific chemicals that might be harming their unborn children. Gallagher expressed skepticism that vaccines had anything to do with her own children's autism. "It's possible that vaccines are a factor in some families, but I don't think that's what happened with my two children", she told me. "I brought two autistic babies back from the hospital."

So with the support of local parents, the CDC team focused on water quality. And they had a specific hypothesis about the nature of the contamination. The CDC team member from Agency for Toxic Substances and Disease Registry (ATSDR) had written a paper just a few years before that linked trihalomethanes (THMs) to a variety of birth defects, including neural tube defects. Frank Bove (who according to Gallagher had two autistic children himself) believed that these neural tube defects could be the key missing piece in the puzzle. Bove consulted with Patricia Rodier, a researcher from Rochester who had worked on toxins that she believed could cause neural tube defects in autism. And the ATSDR report on Brick went on at some length about their concerns over THMs (a pervasive toxin that Bobbi Gallagher knew was elevated in the local water supply) and neural tube defects. But in Bove's particular approach to the analysis of Brick's autism cases and THM exposure, there was no smoking gun. In fact, any way they cut the data, they could find no link between the elevated THM rates in the local water supply and the local autism cases.

In short, ATSDR's quest for a singular environmental toxin that might provide an easy explanation for Brick's autism problem came up empty. So despite autism rates in Brick that were far higher than anything ever seen before, CDC and ATSDR were unwilling to declare the Brick community an autism cluster. To this day, autism rates in NJ are among the highest in the nation and among the highest reported anywhere in the world (one recent survey reported a rate of 1 in 93 children). But in part because no obvious and easy toxin presented itself for blame and removal, the CDC took no position. And they pursued the issue no further.

The second question on the CDC's plate was the question of the rising trend in autism rates. In Gallagher's support group meeting in 1997, everyone had remarked on the unusually large numbers of 3-4 year old cases. And by January of 1999, the CDC had a great deal of data on ages and birth years of their affected population. Their conclusion on trend? In a classic bit of statistical doublespeak, they declared that there was no support for higher autism rates in younger children. "Age-specific rates were calculated for preschool (3- to 5-year-old) and school-aged (6- to 10-year-old) children...CIs [confidence intervals] for the 2 age groups overlapped, indicating that the prevalence rates for the 2 age-groups were not different."

But how could this be true? It seemed to fly in the face of everything observed by the parents and professionals on the ground, not to mention the hints that the CDC had been hearing for years about rising autism rates all over the country. Unlike the search for environmental toxins in the

water, there was nothing all that complicated about the trend. Either there were more cases or there weren't. And if the rates were rising, however hard it might be to pin down the cause, it was important to keep looking, because too many children were sick.

In mid 2002, it occurred to a few of us at SafeMinds that the CDC's conclusion in their Brick Township report was likely to be flawed. Not only was the rising trend apparent in their data, there were also a number of odd elements in their design and write up. For one thing, the age groupings were strange—separating the sample into two groups of unequal size, 3-5 and 6-10 year olds. Why would they not divide the population into equal sizes, putting 3-6 year olds and 7-10 year olds together? For another, as I had learned in examining Lisa Croen's claims of diagnostic substitution in California, autism time trends can be easily misinterpreted if the analysts don't factor in the lag time that the youngest children face in getting recognized (the technical term is "ascertainment bias"). What if the Brick team, as most survey teams had done before them, had simply undercounted three year olds?

So Sallie Bernard sent an email to Frank DeStefano of the CDC, whom she had met at a recent meeting. She asked him what would happen to the Brick rates with 3 year olds removed. And he responded in a May 10, 2002 email, "For overall ASD, the prevalence (sic) were: 10.2 per 1,000 among children 4-6 years old, 4.4 per 1,000 among those 7-10 years old." Sallie promptly thanked him and, noticing that this rate differential seemed larger than the published study, asked him if these were statistically significant. DeStefano's response was telling.

"The results are based on 35 cases out of an estimated 3442 children 4-6 years of age, and 19 cases out of an estimated 4272 children 7-10 years of age. ***The difference in prevalences noted below is statistically significant.***" [emphasis added]

In other words the published conclusion changed completely if you simply removed a single age group, the three year olds.

Despite providing a stunning admission, DeStefano had still not given us what we really wanted, which was the breakdown by age category. So Sallie asked him again. And a few months later, she received this response from Marshalyn Yeargin-Allsopp.

"Hi Sallie, Happy New Year! Frank Destefano has asked me to respond to your question about rates of autistic disorder for Brick Township.

They are: (per 1000), rounded

3 yo	2.5
4 yo	6.1
5 yo	7.8
6 yo	7.0
7 yo	6.4
8 yo	2.0
9 yo	----
10 yo	----
TOTAL	4.0"

This was even more of a shocker. What Yeargin-Allsopp had revealed was that there was not a single case of full syndrome autism in the entire Brick Township population of nine and ten year olds. This was a different case definition than the one DeStefano had given us, which included PDD NOS and Asperger's cases. But it provided clear statistical support for the parental concern over the unusual number of cases in the younger children. And here it was in black and white -- the CDC had this data all along.

So on the second crucial part of their charge, the evidence was clear. The CDC knew there was an autism epidemic in Brick Township in 1998. And they neither said nor did anything about it. In fact, they did exactly the opposite: they used a clever bit of statistical trickery to cover it up.

How clever was it? Well once you have the real trend data, you can figure out how hard the CDC had to work in order to report a result that said there was no trend. And in the months between January 1999 and April of 2000, the CDC figured out just about the only possible way to claim that autism rates weren't rising. They took the 6-10 year group, one where autism rates rose from just plain zero to 1 in 143 and put them into one bucket. They took the 3-5 year old group, which due to ascertainment bias had a declining rate (from 1 in 128 to 1 in 394) and put them into another bucket. And they compared these two ratios and reported that there was no significance to the rising trend. And if you run the statistics on just this arrangement of the data, they are correct.

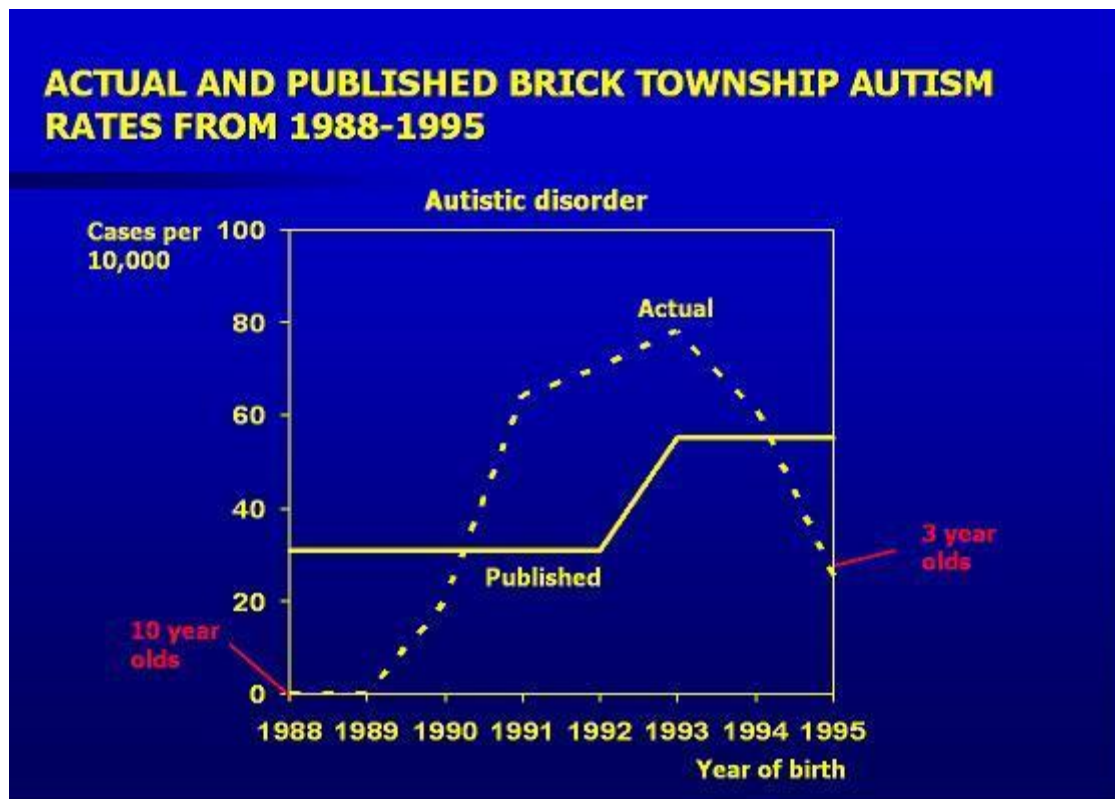
But the problem with this approach is that it's too clever by half. Virtually every other reasonable grouping shows a significant increase.

- DeStefano's analysis comparing ASD rates in 4-6 year olds with 7-10 year olds gave a significant increase with a 99% confidence level (statistical "significance" kicks in at 95% confidence).
- If you take the full syndrome autism group and divide it into two equally sized buckets, comparing 3-6 year olds and 7-10 year olds, you also get a significant result with 99% confidence.
- If you take the 5-6 year old group of full syndrome kids and compare it to the 9-10 year old kids, you get an even more significant finding, more than 99.9% confidence.

As the saying goes, there are lies, damned lie and statistics. If this wasn't a cover up, I don't know what else to call it.

For some, myself included, a picture is worth a thousand words. And if the problem in Brick was indeed more than a cluster, if there was a broader national trend towards rising autism rates, then what matters is not just the age of the Brick children, but their birth years. A more consistent national trend would be revealed if we could find similar changes in autism rates in the same birth years. And a clear picture of the increasing trend would help us identify the kinds of environmental causes that weren't just local elevated toxins in the Brick water supply.

The Brick study provided the first data that could paint this picture and show the specific turning point in autism rates. The age groupings in the Brick team's study were based on the "attained age in 1998", so the ages are easily converted to birth years. Every child who attained the age of three in 1998 was born in 1995, the four year olds were born in 1996 and so on, up to the ten year olds, who were born in 1988. The chart below shows the data Yeargin-Allsopp sent to Sallie Bernard and compares it to the data the CDC published. As you can see, the rates exploded in the 1990-94 birth years and then dropped off a bit in the 3 year olds, due to the ascertainment effect. Looking at the numbers year by year (the dotted line), and comparing them to the published rates (the flat solid line), it's easy to see just how deceptive the CDC's reported findings truly were.



As I said in part 1, there is a moment of truth in the life of any institution. And here was the moment for the CDC, the crucial point "when they proceeded from uncertainty, to confusion, to (perhaps if we're charitable) error and then to a policy commitment." In this case, attributing the stage after confusion to error is more charitable than the CDC deserves. Faced with the evidence pointing to the worst childhood epidemic in modern memory, the CDC chose to cover it up. When you have the real data, the numbers literally jumped off the page. But the only published finding was "no trend", the only commentary, bland reassurance.

What kind of pressure would make professional people do something like this? After such a diligent and responsive start, such a spirit of openness and candor, what moved the CDC team to put their head in the sand and walk away?

It's worth remembering what was happening in the period between January 1999 and April 2000. Most of Washington DC was consumed with the impeachment proceedings ending in Clinton's acquittal on February 12, 1999. In March 1999, just two months after the CDC press conference, the California Department of Developmental Services issued their own report showing the sharp increases of autism rates in California. A few months after that, in July 1999, the Public Health Service announced its plans to remove thimerosal from childhood vaccines. So as the team completed their work, it's almost certain that the public posture the CDC would take in the Brick report took on added importance. After all, as the chart shows, the real surge in Brick was in line with the expansion in the required immunization program, certainly correlated with thimerosal exposure. So there's little doubt that the CDC was worried about its own role in provoking an autism epidemic. At the same time, as the durable evidence of elevated rates in New Jersey have shown, the local trend was also perhaps part of something more specific to the Brick environment. Speculation aside, however, this was a moment of choice. And in a moment that required continued professionalism, openness and candor, something else happened. It was pretty pathetic.

In April 2000, after many months of silence Bobbie Gallagher got a call from the CDC. They were coming to town to release their study, both the CDC prevalence report and the ATSDR analysis of local toxins. They came to her house, gave her two lengthy documents, asked her to respond in the moment if she had any questions. They confessed that the autism rates in Brick were three times higher than rates they were seeing elsewhere. But they had no plans to do anything more about it.

Then they left the Gallagher's' house to go to the public meeting, where they took the same basic approach. They made no presentations, simply put the two reports on the table and made themselves available for questions. They had two sessions, one for the press and one for the residents.

And at the front of the room, Gallagher reports that there were two groups of people. One was the familiar team, Bove, Mars, Bertrand, who had done the work and been part of the initial outreach. Next to them was another group "we had never seen before." Their job, according to Gallagher, was to watch the original group and "make sure nobody said the wrong thing." At 8:00 PM, the session ended and "you've never seen a group leave a room so fast."

"And we never heard from any of them ever again."

Mark Blaxill is Editor At Large for Age of Autism.