

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



Managing Editor's Note: In light of the resignation of CDC Director Dr. Julie Gerberding, we decided to re-run this post from Mark Blaxill. Part 2 runs tomorrow.

(Part 1 of 2)

By MARK BLAXILL

With the recent announcement of the "largest ever" study to investigate the causes of autism, run through Kaiser Permanente (the HMO that lost vaccine safety data implicating thimerosal in harming children) and led by Lisa Croen (the epidemiologist who first attempted to deny the autism epidemic with faulty data), sometimes you just want to shake your head and wonder, what on earth is going on down in Atlanta?

The Centers for Disease Control (CDC) was once a proud and prestigious agency, staffed by the most elite corps of disease fighters on the planet, manning the front lines of the most threatening health problems facing mankind. Today, riven by dissension and ridiculed by many, the CDC has made a mockery of itself in failing to get to the roots of the most critical public health challenges of the day, including, but not limited to, autism. The consequences of its failures are profound. Morale has deteriorated and Congress has been investigating the agency for months.

Reflecting their loss of trust in the CDC's objectivity, autism advocacy groups have actively lobbied to reduce (and even zero out) CDC funding in the Combating Autism Act. The CDC has dual responsibility for monitoring vaccine safety and promoting the vaccine schedule; at the same time it's also responsible for surveillance on diseases like autism. In light of widespread concern over the link between autism and vaccines in the autism parent community, when the CDC announces that it's launching a new effort to find the cause of autism, it's hard not to think of OJ Simpson offering a reward for finding his wife's killer.

It was not always so. Indeed, in the midst of the AIDS epidemic, it was the CDC that took the lead—often against the intransigence and conservatism of NIH researchers—in tracking down the causes of the AIDS epidemic and taking steps to reduce its toll on society. For many years, CDC was held up to the world as a model government agency. Yet in autism, we have truly seen the downward spiral of the agency reaching its nadir: defensive, secretive and non-responsive to a health crisis in full flower. There are undoubtedly larger forces affecting the agency and its leadership. But if (as I believe to be the case) there are turning points in the lives of large institutions, critical crossroads at which difficult choices are made, then the CDC's handling of the autism epidemic is certainly one such turning point. Poor choices at crucial moments can lead, not only to negative consequence on a specific issue, like autism, it can cause the institution to lose its way. In a way, autism has been both a strategic and a moral problem for the CDC. For it's in the autism epidemic, I would suggest, that the CDC has truly sold its soul.

All of which leads me to ask the question, when did the CDC make this choice? What was the point in the history of autism when CDC leaders had the chance to honor its long history and raise the alarm over the autism crisis? Some would point to the infamous Simpsonwood meeting in the summer of 2000, where evidence of thimerosal's neurotoxicity, already tampered with in ways unknown to the meeting participants, was swept aside. I have certainly been in the forefront of the critics of the CDC work on vaccine safety issues, but I believe the CDC was already well past the turning point by Simpsonwood. I would suggest we need to look a bit earlier to find the CDC's crossroads in autism. For that, we need to look couple of years before the summer of 2000 and a bit further north.

The CDC lost its way on autism in Brick Township, NJ.

Three years ago, I attended a presentation outside of Boston given by Marshalyn Yeargin-Allsopp, the CDC's lead autism epidemiologist. In the course of a lengthy party-line talk about autism ("we simply don't know if autism rates are going up or if it's just better diagnosis"), she said something that surprised me. "About ten years ago, we began to hear concerns from around the country that people were seeing more cases of autism", she said. I raised my hand from the audience and suggested that maybe ten years was enough time to move beyond the stage of ignorance on something this important. She snapped at me, a revealing moment in itself, and plowed through the rest of her 200 page presentation without pausing for a breath (or another question). But her comment got me thinking. Certainly, the CDC, the agency on the front line of all emerging public health problems from HIV to SARS to e. coli in a bad crop of California spinach, would have had at least some idea that there was an autism problem far before any of the rest of us did. And that leads me to my question for the day.

What did the CDC know about the autism epidemic and when did they know it?

It's a crucial question. For it is in the specific decisions that the CDC made-- when they proceeded from uncertainty, to confusion, to (perhaps if we're charitable) error and then to a policy commitment--that we might find that fateful moment of moral choice: the moment when CDC chose to put its own bureaucratic agenda ahead of our children. And from Yeargin-Allsopp's intriguing comment, I now knew that CDC was at least beginning to hear reports of rising autism rates around the year my own daughter was born, in 1995.

I know little about the CDC's activities in the years up to 1997, and there are few signs of a broader recognition of an autism problem that one can find before then. But in the fall of 1997, at a parent support group in eastern New Jersey, a few people started commenting about how many new autism cases seemed to be cropping up in Brick Township, and how there seemed to be an unusual number of 3-4 year old children with a new autism diagnosis. One of the attendees at the support group, a mother named Bobbi Gallagher who had two young children with autism, was struck by this coincidence. Living in New Jersey (although Brick is on the Jersey Shore, not the polluted stretch of highway along the New Jersey Turnpike that makes a mockery of New Jersey's nickname, "The Garden State"), the thought of environmental contamination came naturally to mind and she wondered if there might not be a cluster of autism cases in Brick. Perhaps, she thought, there was something in the water. So she resolved to do something about it.

She decided to send around a survey to see if she could count the autism cases in all of Brick, a town of some 70,000 people.

So as the new 1997 school year was starting, Bobbi Gallagher distributed her survey form everywhere she could think of in town. And in a few short weeks, she got a surprising result. Based on the responses to her impromptu survey, she counted over 40 autistic children in Brick Township alone and over 30 who were just three or four years old. Armed with these results, Gallagher formed a group called the Brick POSSE (Parents of Special Services and Education) and organized a meeting at the local library a couple of months later. They contacted Eric London at the National Alliance for Autism Research (NAAR) who in turn invited a number of academic epidemiologists. To a full house at the library meeting, Bobbi Gallagher shared her findings. One of the epidemiologists present, Craig Newschaffer, decided the numbers were disturbing enough to contact the New Jersey Department of Health and Senior Services, who in turn contacted the CDC. In the meantime, the Brick POSSE arranged a meeting with their congressman, Rep. Chris Smith, who invited them to a meeting in his office in Washington.

Within weeks, a more organized response took shape. Bobbie Gallagher received an invitation to another meeting in Washington, this time in New Jersey Senator Robert Toricelli's office. Gallagher remembers the date for this meeting vividly, April Fool's Day, 1998. And when she walked into the room she was astonished at how quickly plans had emerged. She had expected again to play the role of supplicant, pleading with the government officials to take action. Instead, she found a prompt and aggressive action plan being put on the table. In the room that day were representatives from multiple departments within the CDC who had come to the Senator's office equipped with a multi-part plan, the first part of which was a prevalence study for Brick Township, an in-depth survey of the town's autistic population that would pick up where Gallagher's survey left off. CDC had identified a core team of staffers to lead the effort, including Jacquelyn Bertrand and Marshalyn Yeargin-Allsopp from the National Center on Birth Defects and Developmental Disabilities (NCBDDD) and Frank Bove from the Agency for Toxic Substances and Disease Registry (ASTDR). Their proposal: to diagnose every child with autism in Brick Township between the ages of three and ten years old. They would start canvassing for cases and conducting interviews beginning with the start of the 1998 school year in September. And they planned to move quickly (at lightning speed really), to have their initial results ready by the end of the year.

They were true to their word. Two diagnosticians, Dr. Bertrand and Dr. Audrey Mars from the nearby Robert Wood Johnson Medical School, spent several days a week diagnosing children in the fall of 1998. And by January 12, 1999, the CDC had confirmed the findings of Gallagher's initial survey. Out of an initial estimated Brick population of 6,000 children from 3-10 years old, they had found over 40 cases of autism, giving a preliminary rate that was 12 times the estimated prevalence in the rest of the country. "I think there is a cluster here. I don't know why," lead investigator Bertrand said in an article by the Associated Press the next week. "If [we find] it's something that can be taken out of the community, that will be done," she said. According to AP she also added another intriguing tidbit: that "the researchers are eager to solve the puzzle here because of escalating calls the last few years about possible, but less credible, clusters elsewhere in the nation."

It all seemed to Gallagher like a dream: the cavalry had arrived and somehow they were going to get to the bottom of the issue. But then, something strange happened. Suddenly, the lines of communication with the CDC team went dark. After several months of intensive planning, intensive collaboration and rapid response, the CDC team told Gallagher that they were not at liberty to discuss the results with the parents any longer. According to Gallagher, one of the CDC staffers informed her that the mere mention of the word "cluster" had provoked a reaction from the higher ups within the CDC. Apparently, there was now even a debate as to whether they could use the word "elevated" when describing the prevalence rates. So from January 1999, until the release of the final study in April of 2000, there was no more interaction with the CDC. Not a single word.

Perhaps it was concern about the legal questions raised if there was indeed something in the water (class action attorneys had begun recruiting local families). Perhaps the Brick results weren't a cluster after all but part of a larger pattern that caused a more generalized concern within CDC (maybe it wasn't the water after all, since in February of 1998 the Lancet has published Andy Wakefield's controversial study implicating vaccines in autism). But there was no doubt about the silence coming from Atlanta. Something had changed the behavior of the CDC team. And it raises an interesting question. What did the CDC learn about autism rates in Brick Township and what did they do with their newfound data?

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In Part 2: a discussion of the specific numbers in CDC's Brick Township report and what they should have told the world about the autism cases that they found in Brick.

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