

Evidence of Venom:

An Open Letter to David Kirby, by Kathleen Seidel

May 29, 2005

http://www.neurodiversity.com/evidence_of_venom.html

----- Original Message -----

From: "Kathleen Seidel" <anima@neurodiversity.com>

To: "David Kirby" <dkirby@nyc.rr.com>

Cc: <george.Witte@stmartins.com>

Sent: Sunday, May 29, 2005 3:30 PM

Subject: Evidence of Venom

Dear Mr. Kirby,

I am the mother of two teenagers, one with a diagnosis of Asperger Syndrome. I am writing to you not to debate the mercury-autism causation hypothesis, but to express my concerns about the impact and implications of your efforts to promote your book, Evidence of Harm, and the efforts of members of the Evidence of Harm discussion list on Yahoo! — your ad hoc, grassroots publicity team.

While I appreciate your concerns about thimerosal and the concerns of parents who have legitimate reason to believe that their children have suffered from vaccine reactions, I would like to remind you that there are a great many parents who do not suspect vaccines as a cause of their children's autistic spectrum condition. I am one of those parents, and I can hardly express to you how offended I am by the aggressive media campaign being pursued by those who seek to hold pharmaceutical companies liable for the fact that their children are autistic, by attempting to persuade the general public (which encompasses voters and potential jurors) that most autistic people are victims of mercury poisoning.

It is a legal and political strategy with several main elements:

§ Promoting popular perception and scientific re-definition of autism as a disease process, and undermining support for other areas of autism research: "Although we all know as parents and advocates that autism is an immune mediated disease, it is important to get that well established in mainstream science and medicine. Moving the paradigm away from chasing the illusive autism gene and silly psychological studies, i.e., scientific masturbation, is of paramount importance."

<http://groups.yahoo.com/group/EOHarm/message/1496>

§ Promoting popular perception and scientific re-definition of autism as a phenomenon that is primarily a consequence of thimerosal poisoning, in order to attract new litigants and political supporters: "...once causation is established in vax court or

state/federal court, then we will be able to place overwhelming political pressure to amend vica to either extend the poultry 3-year statute of limitations or reopen briefly so that any mercury-injured kid can have access to the process."

(<http://groups.yahoo.com/group/EOHarm/message/344>)

§ Destroying the individual and collective credibility and reputation of scientists, public health professionals and health care practitioners who have supported vaccination initiatives: "Our main job is to destroy the credibility of the vaccine industry and that's just what EOH has done."

(<http://groups.yahoo.com/group/EOHarm/message/719>)

§ Convincing the public that autism was practically nonexistent until the beginning of widespread vaccination in the mid-twentieth century, and that we are now in the midst of an "autism epidemic": "...everyone does not even know that there is an autism epidemic and at a practical level, simply establishing that fact remains the most important work we can and must do."

(<http://groups.yahoo.com/group/EOHarm/message/1761>)

§ Denying the very possibility that there exist a significant number of adults whose early developmental pattern resembled that of children currently diagnosed with autistic spectrum conditions, for without that denial there can be no "epidemic." This is a denial publicly pioneered by Mark Blaxill

(<http://bmj.bmjournals.com/cgi/eletters/323/7313/633>) that you have repackaged and reasserted in your recent essays in The Huffington Post and British Medical Journal (http://www.huffingtonpost.com/theblog/archive/david-kirby/vaccines-and-autism-ques_1325.html, <http://bmj.bmjournals.com/cgi/eletters/330/7500/1154>).

§ Using deliberately emotional appeals such as the "Recovered Kids" video (<http://www.autism-recoveredchildren.com/>) to persuade the general public of the "truth" that autistics are poisoned and in need of detoxification: "the more visual and auditory we can make the message, the more people we can reach and the stronger impact we can have on them"

(<http://groups.yahoo.com/group/EOHarm/message/2856>).

It is a legal strategy undertaken with little regard for the fact that a significant proportion of families have no particular reason to suspect thimerosal poisoning as the cause of a family member's autism. I have read many online newsgroup posts (including posts to the EOH list) written by parents of autistic children who do not describe witnessing any specific reaction at the time that shots were administered to their children, but who have become convinced of the vaccine hypothesis due to the publicity efforts of vaccine litigants. These parents are now consumed with guilt that their good-faith decision to vaccinate their children might have had damaging consequences, and rage at those individuals whom they presume misled them and inflicted damage upon their children, whether that guilt and rage are warranted or not.

It is also a legal strategy undertaken with little regard for the potential long-term, stigma-

perpetuating impact upon those autistic people and their family members who are not inclined to believe that all autistics are poisoned. I have observed numerous instances in which vocal proponents of the autism=poisoning hypothesis have displayed outright contempt for anyone who might have come to their own conclusions about their and their family members' lives, and I will cite many of these instances in this letter.

For example, here is a comment by Lujene Clark, responding to Kevin Leitch, a British father of an autistic child; she and other EOH list members descended en masse upon Mr. Leitch after a blog entry he had written was mentioned on the list (<http://www.kevinleitch.co.uk/wp/?p=146>, <http://groups.yahoo.com/group/EOHarm/message/1014>):

"...if you remain in denial you don't have to extend yourself or take responsibility to heal your child because it is so much easier to blame "bad genes" and accept your child's fate. Or worse, try to get your child to accept his "genetic" fate. That is a COP-OUT. Your child deserves better. Get off your lazy bum and start to heal the biomedical problems of your child!!"

When Mr. Leitch stated that he recognized autistic traits in members of his extended family, Mrs. Clark replied,

"it seems apparent from reading your reply there is a history of serious psychiatric illness in your family. My apologies, I would not have attempted to engage in rational discussion had I known you were affected."

Now, this is quite a toxic attitude to have towards disability, towards evidence of the genetic transmission of devalued characteristics, and towards parents who think for themselves. Do you share this attitude?

Here is another example:

"I believe that most of the parents who are in denial are that way because they have the same genetic predisposition and are toxic themselves and have "symptoms" which is why they believe it is genetic... they see it in themselves. Also, from what I have personally seen, people who are mercury poisoned are defensive and appear in denial in general." (<http://groups.yahoo.com/group/EOHarm/message/1337>)

Is this an analysis with which you concur?

Not all autistic citizens and their families feel that we need "heroes" who loudly shout that the presence of autism in a family is tantamount to poisoning, and that it renders all that family's members incapable of rational discourse. Not all of us respond positively to "heroes" like Dr. Rashid Buttar, who invokes the image of an autistic person "flipping burgers" in his sales pitch for DMPS cream, a chelating agent promoted as a cure for autism:

"Our success has been all under the age of nine, nine or under. Now since then, when I presented to Congress I told them that I didn't think this would be effective for older children because the older children would use it, I didn't see — they got better, they started talking, but they're not in my book considered normal. They can read, but they'll never do much more than flip hamburgers for a living, that type of thing. They won't reach their full potential. But now I'm finding that actually we have a couple of kids, I have three kids that are over the age of eleven, and they're all having rapid response — actually they're all children of doctors — and they're all seeing very good results." (presentation mentioned at <http://groups.yahoo.com/group/EOHarm/message/1003>; see the entire presentation at <http://www.autismmedia.org/buttar5aq.html>)

Such appeals to parental fear and status consciousness - pitting the image of the burger-flipping "abnormal" against the image of the doctors' children who are making speedy progress to "normality" - demean both distinguishably autistic individuals, and individuals who earn an honest livelihood in low-status jobs. This kind of thinking can only serve to perpetuate stigma. Unfortunately, it is an attitude that pervades the daily discussions on the mailing list established to coordinate independent publicity efforts for your book. These publicity efforts include the upcoming "Evidence of Harm Day" aimed at boosting the book's sales ranking, by encouraging parents to purchase multiple copies (<http://groups.yahoo.com/group/EOHarm/message/2600>).

Indeed, the Evidence of Harm discussion list has evolved into a staging ground for ideological assaults, ad hominem attacks and mob actions against parents who express their doubts publicly about the autism-thimerosal hypothesis. Witness the flurry of outraged comments on Mr. Leitch's blog, and the May 18 collective descent on the Parents Magazine online forum, where a parent, "dangermama," had posted a forthright, informed response to another parent's inquiry about vaccinations (<http://www.parents.com/community/boards/thread.jspa?forumID=78&threadID=277579>). That campaign all started with a plea to members of the EOH list: "Dear Gang... If anyone is up to giving this person a online beating please chime in" (<http://groups.yahoo.com/group/EOHarm/message/2547>). One EOH list member signed on to Parents as "myboycody," then made over 70 posts to that board over the following 48 hours (<http://groups.yahoo.com/group/EOHarm/message/2556>); another returned to the EOH list, admitting, "I love telling people off its great stress relief" (<http://groups.yahoo.com/group/EOHarm/message/2563>).

Is this the kind of publicity campaign you envisioned, the kind of moral support you welcome?

Autism and autistics have been described on the EOH list as:

"government mercury vaccine poisoned kids"

(<http://groups.yahoo.com/group/EOHarm/message/97>)

"Parent's Worst Nightmare Syndrome PWNS or Living He**"

(<http://groups.yahoo.com/group/EOHarm/message/418>)

"an equal opportunity disaster" (<http://groups.yahoo.com/group/EOHarm/message/543>)

"walking bio-hazards" (<http://groups.yahoo.com/group/EOHarm/message/1469>)

Parents who do not agree with your associates have been variously disparaged on the EOH list as:

"in denial" (<http://groups.yahoo.com/group/EOHarm/message/2234>)

"clueless" (<http://groups.yahoo.com/group/EOHarm/message/1024>)

"embittered and not entirely rational"

(<http://groups.yahoo.com/group/EOHarm/message/153>)

negligent (<http://groups.yahoo.com/group/EOHarm/message/2197>)

"flat-earth(ers)" (<http://groups.yahoo.com/group/EOHarm/message/2172>)

"parents (who) have not yet learned the facts"

(<http://groups.yahoo.com/group/EOHarm/message/1771>)

"brainwashed" (<http://groups.yahoo.com/group/EOHarm/message/2157>)

"blinded by hate" (<http://groups.yahoo.com/group/EOHarm/message/2574>)

"just taking the 'safe,' mainstream road of thought for not knowing better"

(<http://groups.yahoo.com/group/EOHarm/message/2155>)

"desperate" (<http://groups.yahoo.com/group/EOHarm/message/2195>)

inherently lacking in credibility (<http://groups.yahoo.com/group/EOHarm/message/1331>)

"old school" (<http://groups.yahoo.com/group/EOHarm/message/3009>,

<http://groups.yahoo.com/group/EOHarm/message/3023>)

"an ugly, feisty fiend" (<http://groups.yahoo.com/group/EOHarm/message/3179>)

"unenlightened" (<http://groups.yahoo.com/group/EOHarm/message/3183>)

Researchers and practitioners in the areas of cognitive psychology, neuropsychology, genetics, medicine, public health, and education, have been described on the EOH list as:

"lazy" (<http://groups.yahoo.com/group/EOHarm/message/2133>)

"vaccine barbarians" (<http://groups.yahoo.com/group/EOHarm/message/190>)

"cheap whores" (<http://groups.yahoo.com/group/EOHarm/message/1888>)

motivated only by a paycheck (<http://groups.yahoo.com/group/EOHarm/message/222>)

"high-minded Fascist germ freaks"

(<http://groups.yahoo.com/group/EOHarm/message/1345>)

conducting "silly psychological studies"

(<http://groups.yahoo.com/group/EOHarm/message/1496>)

researching "'pie in the sky' stuff unlikely to yield actionable results"

(<http://groups.yahoo.com/group/EOHarm/message/2008>)

disseminating "malicious public relations hyperbole"

(<http://groups.yahoo.com/group/EOHarm/message/1502>)

possessed of "retrograde views" (a specific slur against Harvard researcher Dr. Margaret Bauman) (<http://groups.yahoo.com/group/EOHarm/message/1504>)

spiritually inferior (<http://groups.yahoo.com/group/EOHarm/message/155>)

"pharmaceutical and medical killers"

(<http://groups.yahoo.com/group/EOHarm/message/2705>)

Autism organizations such as the National Alliance for Autism Research, Cure Autism

Now, and the Autism Society of America, have been characterized on the EOH list as:

"establishment" (<http://groups.yahoo.com/group/EOHarm/message/883>)
"secular herdsmen" (<http://groups.yahoo.com/group/EOHarm/message/1894>)
"carpet-bagging rackets" (<http://groups.yahoo.com/group/EOHarm/message/1975>)
"co-opted" (<http://groups.yahoo.com/group/EOHarm/message/1667>)
"autism mafia" (<http://groups.yahoo.com/group/EOHarm/message/1502>)
"not representing our children's interests"
(<http://groups.yahoo.com/group/EOHarm/message/2008>)
possessed of conflicts of interest
(<http://groups.yahoo.com/group/EOHarm/message/1453>)

Indeed, all those who might fall into the category of "the book's antagonists" have been called:

"those motherfuckers" (<http://groups.yahoo.com/group/EOHarm/message/69>)

Do you concur with these vilifications against parents, researchers and service providers who disagree with the thimerosal litigants' hypotheses, and/or whose work is focused on different areas than mercury? Not once have I read a post where you suggest that it might be appropriate to avoid insulting parents of autistic children in connection with publicity efforts for your book. When two different list members ridiculed Dr. Melinda Wharton of the CDC with comments about the Public Health Service uniform she wore during a Congressional hearing (<http://groups.yahoo.com/group/EOHarm/message/2393>, <http://groups.yahoo.com/group/EOHarm/message/1295>), not once did you or any other EOH list member suggest that it might be inappropriate to stoop to childish, sexist jeering in connection with publicity efforts for your book. When an EOH list member made the statement, "Lenny... if it's genetics, how did such sharp witted parents have such dull witted offspring?" (<http://groups.yahoo.com/group/EOHarm/message/996>), not once did you or any other EOH list member make note of the fact that referring to autistics as "dull witted" is crude and demeaning, or at the very least make it clear that this is not the sort of characterization of autistic people that you would want associated with publicity efforts for your book. When an EOH list member revealed her plan to distribute flyers advertising Evidence of Harm at a recent lecture by Temple Grandin on Long Island, not once did you suggest to her how inappropriate it would be for her to promote your book at an event featuring another author represented by another publisher, without first obtaining permission from the event's sponsors (<http://groups.yahoo.com/group/EOHarm/message/3009>).

You have made many public assertions that you have adopted a neutral stance on the thimerosal issue. However, consideration of the discussion on the EOH list leads me to conclude that the "neutrality" is only for public display and that many of the autism=poisoning proponents regard you as their mouthpiece. In response to an EOH list member's complaint, "Whose side is he on? He needs to stop misleading the public that vaccines are now virtually mercury free" (<http://groups.yahoo.com/group/EOHarm/message/1582>), another stated, "Well from

what little I know he is on 'our' side"

(<http://groups.yahoo.com/group/EOHarm/message/1668>). Another list member wrote, "Kirby may have written it, but EOH is OUR book"

(<http://groups.yahoo.com/group/EOHarm/message/2923>). Although you might take issue with these statements, they reveal the impression that you have succeeded in conveying to at least two active members of your support network. This is an impression reinforced by your reference to Atlanta, home of the CDC, as "the belly of the beast" (<http://groups.yahoo.com/group/EOHarm/message/279>).

If you were truly objective, why is it that Lyn Redwood, co-founder of Safe Minds, was identified as the contact person for <http://www.evidenceofharm.com> until just recently? (The WHOIS record changed after I made note of the domain's contact information on a post to the Health Fraud mailing list, also frequented by a number of your EOH list-mates; although you are now named as contact person, the address remains that of another "mercury mom" who maintains the site.) If you were truly objective, why would you begin the discussion on the EOH list with, "Let's hope the 'other side' chimes in," rather than, "Let's hope both sides chime in"

(<http://groups.yahoo.com/group/EOHarm/message/26>)? If you were truly objective, why would there be so little evidence in your public pronouncements that you ever sought to acquaint yourself with adults with autistic spectrum diagnoses, rather than blithely parroting Mark Blaxill's "hidden horde hypothesis"? Why would there be so little evidence in your public pronouncements that you have sought to acquaint yourself with parents who have chosen not to pursue biomedical interventions with their offspring, or parents who recognize that autism was indeed "born in their house," and not inflicted upon the family by a villainous conspiracy? Lenny Schafer has exhorted EOH list members to "keep the focus on the good guys and the bad guys"

(<http://groups.yahoo.com/group/EOHarm/message/391>). According to this world-view, the "bad guys" are not only the supposed Goliaths of government and the pharmaceutical industry, but also many thousands of autistic people who do not identify themselves as victims of poisoning, and thousands of loving, conscientious parents — parents whose life experience does not include "evidence of harm" by vaccines, who have a different perspective on their lives and on the diagnosis that they or their family members happen to share with others, and whose private medical choices have not included elaborate, expensive, experimental detoxification and nutritional supplementation regimens.

Your many years of work for the Advocate suggests that you are alert to issues affecting the gay community. May I therefore suggest a thought experiment. For one week, every time you read an instance of the word "autism" or "autistic," replace it with "homosexual," "gay" or "queer." I have already done this for you on the bumper sticker that appears below; it is modified from the one that Lenny Schafer recently developed and distributed to participants on the Evidence of Harm mailing list — "My child was poisoned by mercury in vaccines, but everyone calls it Autism," juxtaposed with an image of a skull and crossbones. I provide this image not because I believe the message it appears to convey, but in order to encourage you to consider how it feels for an autistic person to hear incessant, gruesome, emotionally charged descriptions of autism by non-autistic individuals who regard autism as an unmitigated tragedy, as completely

unacceptable, descriptions that insist that an autistic person's experience of the world is a consequence of poisoning, and whose cognitive and behavioral peculiarities are worthy of utter eradication. Although this may seem far-fetched, like comparing apples to oranges, in fact, homosexuality and autism both constitute forms of social deviance in its strictest definition — that is, deviation from the behavioral patterns of the majority. Homosexuality used to be defined as a "psychiatric disorder" — in fact, Ivar Lovaas, the early developer of behavioral interventions designed to suppress the expression of all autistic behavior, was also a pioneer in the development of reparative therapy, designed to suppress the expression of all homosexual behavior.

I hope that you will consider that when you make public statements about autism, you are presuming to speak about an entire class of people who are autistic for life, not simply the subset of parents and minor children with whom you have become acquainted over the past couple of years. For every parent eager to "recover" their child and "lose the diagnosis," there are autistic citizens who will always have the diagnosis and will always wear the label, and who are affected by the manner in which that label is bandied about by those who hate what it represents to them. People too often talk about "autism" as if it is something separate from autistic people. It is not. And those autistic people and their families — autistic children, the autistic-spectrum adults whose very existence you have publicly questioned, and families like mine — will still be around, still dealing with the stigma of "contamination" that you have helped to promulgate, long after the royalties dry up and you have sailed off to your next journalistic destination.

Sincerely,

Kathleen Seidel

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<http://www.neurodiversity.com>

PS, You may be interested in reading a letter I wrote to the New York Times Book Review in response to their review of Evidence of Harm (http://www.neurodiversity.com/nytimes_book_review_letter.html). You might also be interested in an exchange I had with the folks at the MIND Institute, in response to the use of the phrase "autism epidemic" in a recent press release (http://www.neurodiversity.com/mind_epidemic.html).

