

Congressman Ben McAdams  
9067 South 1300 West  
West Jordan, UT 84088

January 6, 2020

Re: Request for an investigation of research fraud by the Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities (NCBDDD), Autism and Developmental Disabilities Monitoring Network (ADDM) and the University of Utah

Dear Congressman McAdams,

Thank you for your service as my congressional representative. It is with deep sadness that I feel an ethical and professional obligation to report to you and other congressional members the research fraud and retaliation I observed and experienced as a Centers for Disease Control and Prevention (CDC) grant awardee and specifically as the Utah principle investigator from 2002-2013 with the Autism and Developmental Disabilities Monitoring (ADDM) Network.

This story is a complicated one. There are multiple facets to the fraud itself including violations of federal school and privacy laws, intentional falsification of autism prevalence rates with ongoing use of data known to contain significant errors, falsification of federal reports and institutional review board applications, plagiarism, financial fraud, abuse, and retaliation. To support my concerns, I have gathered over 10,000 government documents including records from three court cases (state, federal and the Utah Supreme Court) all against the University of Utah. In August of 2018, a federal jury found that the University had retaliated against me in violation of the Utah state whistleblower law for reporting in good faith waste, fraud, and/or abuse. This federal jury decision was not appealed. Further claims are still pending against the University in state court and discovery is ongoing.

As I now believe I have considerable evidence and documentation substantiating the research fraud reported, I would like to share some of those documents in my possession with you and congress. As an initial first step, this letter and attachments will focus briefly on two key components of the fraud, the CDC covering up violations of federal health and education privacy laws and their complicity in the intentional falsification of autism prevalence rates with ongoing use of data known to contain significant errors. It is my belief the University could not have retaliated against me nor could the other components of the research fraud have occurred without the complicity of the CDC and in particular the participation of the CDC Medical Director, Marshalyn Yeargin-Allsop.

You may be asking yourself at this point in my letter, what would be the motivation for the CDC to behave in such a manner. Again, my answer to that question would be a complicated one, but two obvious answers come to mind with respect to privacy violations and data accuracy errors, respectively.

1) Privacy laws can be complicated, time consuming to follow, and costly in order to obtain informed consent. However, what is clear is that in the world of big research and big business, big data equals big money and big power. There were clear financial motivations to gain access to Utah autism data.

2) The inaccuracies in autism data led to erroneous reports of declining Utah autism rates. Correcting the data errors would have resulted in higher US autism rates supportive of declaring an "autism epidemic". A declaration the CDC has never been willing to make and contrary to their historical messaging. A declaration that supports environmental causality which the CDC has repeatedly downplayed.

Now to briefly summarize the privacy and data accuracy errors. In the summer of 2012, I had reason to believe that three University of Utah researchers, Drs. Bilder, Bakian, and McMahon had illegally copied, ¾ of a million identifiable and highly sensitive health and education records from a restrictive use server designated specifically for Utah CDC- ADDM federal grant activities. The server was in the name of my first CDC grant application, the Utah Registry of Autism and Developmental Disabilities. Federal trial evidence (see attachment) showed indeed these records were copied. To justify the electronic data transfer, a data sharing agreement was referenced that I believe was improperly executed and a key signature probably forged as confirmed by a forensic handwriting expert. The attachment will also provide you with additional documentation about privacy concerns. Ironically and tragically, in 2013 the CDC approved the researchers that I had reported for fraud to become the new Utah ADDM principle investigators. Two of them, Bakian and Bilder, still are receiving grant funding from the CDC.

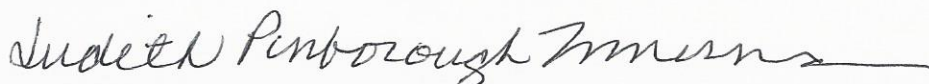
Also, in the summer of 2012, Bakian had been removed from participation in grant activities for cause. Among other things, Bakian had made pervasive data entry errors related to the importation of diagnostic codes used in the CDC ADDM 4-year-old and 8-year-old 2010 study year activities. Significant errors were also found in a CDC validation study in progress which was later published by the CDC with errors. A description of the errors, the impact on autism rates and other research, and the failure of both the CDC and University of Utah to disclose significant methodological deviations are presented in the attachment. To date, the CDC and other researchers continue to use this fraudulent data.

My hope is that the Centers for Disease Control and Prevention will be investigated and held accountable for research fraud and retaliation. I have copied the Congressman from Florida, William Posey, as he is aware of and has documentation of other autism research fraud involving the CDC and specifically Marshalyn Yeargin-Allsop.

Lastly, the public, and most importantly parents and families impacted by autism, deserve better. Our children's most private health and education information should be protected to the full extent of the law and accurate and honest reports of changes in US autism rates are long overdue.

Thank you for your consideration.

Sincerely,



Judith Pinborough-Zimmerman, Ph.D

Cc William Posey, Congressman

ATTACHMENT