From: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Sent: Tue, 26 Apr 2016 14:25:16 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: a few quick updates

Coleen,
A few quick updates on our sensitive topics.

Amanda and I reached out to a few influencers for informal message testing of the vital signs materials. We received some concerning feedback from a very influential and vocal ADHD blogger who used to work with Dr. Frieden in NYC. We are reviewing all of the vital signs materials and exploring ways that we can amend a few statements to integrate her feedback. A bit of a scramble this afternoon. I have looped in Barbara, the press office, vital signs team… as although she is one opinion, I think it is reflective of the feedback that we will receive via bloggers, social media… We will keep you posted as these conversations continue this afternoon.

On another note, here is the latest blog post from Age of Autism. I have been trying to get a sense of the conversation both in NYC as well as in Atlanta following the documentary being shown here. Much here does not make sense.

Dr. Brian Hooker Speaks Out on Developments Concerning CDC Whistleblower Dr. William Thompson

NOTE: From Jefferey Jaxen's blog:

The unexpected piece of information was conveyed by Dr. Brian Hooker during the Manhattan panel regarding recent developments concerning Dr. William Thompson — also known as the CDC whistleblower and focused on in the movie Vaxxed: From Cover-Up to Catastrophe. Dr. Hooker stated:

"***One of the things I asked Dr. Thompson to do in September 2014 was to leave the CDC and bring this all to light so he could come forward, go public, talk to congress, talk to the press directly — he choose not to. Dr. Thompson has been handled and will most likely submit a revised version of his analysis and try to absolve the MMR vaccine in early May 2016. This is typical of what we've seen at the CDC. The CDC analyzes data and when they see an effect they don't like, they reanalyze data and the effect goes away. The CDC has done this historically from Agent Orange to Thimerosal and now to MMR vaccine. I did not want this to come but certainly anticipated that while he was in the CDC it would come. In exchange for what Dr. Thompson is doing — and believe this [info] is a little bit shaky — I believe he will get his own autism research foundation. And so there has been some very, very dubious***

activities that went on because he stayed in the CDC. He also got a major cash reward from the CDC for maintaining his employment he said, until he qualifies for retirement. But there are a lot of things that happened since the last conversation I had with Dr. Thompson which was in September 2014. And I do want to warn you and I do want to anticipate this. But again, it's the same thing we've heard and we've seen from an agency that's been completely captured but the pharmaceutical industry. And it's [CDC] there not to tell the truth but in order to manipulate the public. In order to do what they think the best thing to do is for society."

We will keep you posted throughout the week. Wishing you a safe trip.

-Laura

Laura Baldwin (Zauderer)
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
Phone: 404-498-3976
Email: Lbz7@cdc.gov

From: Weintraub, Eric (CDC/OID/NCEZID)
Sent: Mon, 20 Oct 2014 13:50:29 -0400
To: Gonzalez, Belsie (CDC/OD/OADC); Ghosh, Sudevi (CDC/OCOO/OGC); Lucido, Sal (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Cc: Destefano, Frank (CDC/OID/NCEZID)
Subject: Access to Data - Pediatrics 2004

Here is the email chain on how the process occurred below.

I contacted Birth defects with request.
That request was sent to the following people -----
Autry, Andrew (CDC/ONDIEH/NCBDDD), Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD), Destefano, Frank (CDC/OID/NCEZID); Williams, Susan (CDC/ONDIEH/NCBDDD) and Baio, Jon (CDC/ONDIEH/NCBDDD)

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, January 17, 2014 11:47 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

I would recommend someone cross checking this with the data documentation to verify its accuracy. This only takes a couple of hours to do (i.e., verify the frequency distrubutions in the documentation are the same on the data file) Its been almost ten years since this was done, and I just think that you should check it.. Also, that's the only copy we have, so have Susan copy the data to the public use folder on the CSP.

Andrew R. Autry, PhD
IT Project Manager
CDC/NCBDDD
1600 Clifton Road, MS E-87
Atlanta GA 30329
404-498-3876 (office)
404-936-8499 (cell)

I telework on Fridays and can be reached at 404-936-8499
Overnight address: 1825 Century Center Parkway
Atlanta GA 30345

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Friday, January 17, 2014 11:32 AM
To: Weintraub, Eric (CDC/OID/NCEZID)
Cc: Destefano, Frank (CDC/OID/NCEZID); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

That works for me Eric.

Andy?

From: Weintraub, Eric (CDC/OID/NCEZID)
Sent: Friday, January 17, 2014 11:23 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Destefano, Frank (CDC/OID/NCEZID); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Great! -- Interoffice mail it to me and I'll make a copy in case we get a future request similar to this one (I'll inform you of the requests), then we don't have to bother andy again.
I'm at MS-D26. You fine with that approach?

Thanks,
eric

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Friday, January 17, 2014 9:56 AM
To: Weintraub, Eric (CDC/OID/NCEZID)
Cc: Destefano, Frank (CDC/OID/NCEZID); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: FW: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Eric - We have a CD with the dataset. How do you want to proceed? Thanks, BT

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Friday, January 17, 2014 8:52 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Hi Bill, this is Andy's response:

I left it on a CD with Santrell Wednesday.

Marshalyn

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, January 16, 2014 9:12 PM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Marshalyn – I have e-mailed Andy a number of times over the last several weeks and he hasn't replied to any of my e-mails. This week I also asked Susan and she couldn't find it. Susan suggested I ask Jon. Would you mind following up with Andy? Thanks, Bill

---

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Thursday, January 16, 2014 10:55 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Baio, Jon (CDC/ONDIEH/NCBDDD)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD); Williams, Susan (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: RE: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Andy Autry is best person to know how to access.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, January 16, 2014 10:39 AM
To: Baio, Jon (CDC/ONDIEH/NCBDDD)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD); Williams, Susan (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID)
Subject: Trying to track down the 2004 MMR-Autism-MADDSP public use data set

Jon,

We are having a hard time locating the public use data set that was created from the DeStefano (2004) paper. An external scientist has requested the data set and ISO (Eric Weintraub) has to reply back to the person regarding how to access the data.

I shave retained the original analysis file because all the study documents have both been FOIA'd and Congressional requested a number of times over the last 10 years. We could recreate a public use data set if necessary but I would hate to reinvent the wheel.

Thanks,

Bill

<< File: Destefano (2004) MMR Autism - Pediatrics.pdf >>

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Tue, 22 Mar 2016 15:51:29 -0400
To: Chan, C. Leah (CDC/ONDIEH/NCBDDD); Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD); Baio, Jon (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Antivax Anti-CDC film in Tribeca

Link does not work but you can see trailer by going to AoA.

Andrew Wakefield's movie claiming a cover up of a vaccine/autism link by the CDC will be premiering in April at the Tribeca film festival. Link: http://vaxxedthemovie.com

Details:

"Vaxxed: From Cover-Up to Catastrophe
The most vitriolic debate in medical history takes a dramatic turn when senior scientist turned whistleblower, Dr. William Thompson of the Centers for Disease Control, turns over secret documents, data, and internal emails confirming what millions of devastated parents and "discredited" doctors have long-suspected—vaccines do cause autism.
After the movie: A conversation with creators and subjects of the film.
DATE: Sunday, April 24
TIME: 2:00 p.m.
LOCATION: SVA2"

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Fri, 6 Feb 2015 10:39:41 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: Autism Speaks Urges Parents to Vaccinate Children - ABC News

http://abcnews.go.com/Health/autism-speaks-urges-parents-vaccinate-children/story?id=28751485

From: Jaffe, Harold W. (CDC/OD/OADS)
Sent: Wed, 24 Sep 2014 16:44:25 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Ikeda, Robin (CDC/ONDIEH/OD); Cono, Joanne (CDC/OD/OADS)
Subject: Autism Study Re-analysis

Coleen,

Ileana mentioned to Tom F that your team was doing a reanalysis of the MMR autism study data. He asked when could he take a look at it.

Thanks

Harold

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Tue, 24 Nov 2015 10:58:14 -0500
To: Sniezek, Joe (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Cc: Chaney, Sascha (CDC/ONDIEH/NCEH); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Shapira, Stuart (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Brief summary of IACC meeting -- please share with staff

Hi everyone,

Daisy, Laura Baldwin and I attended the November 17, 2015 meeting of the Interagency Autism Coordinating Committee (IACC). I am representing CDC as one of the federal representatives on the committee and Daisy is my alternate. I updated the committee on some of CDC's recent and upcoming accomplishments/activities and as always was our work is impressive! Below is a brief summary. Please let me know if you have questions.

Regards,

Cindy

- First meeting since the reauthorization under the Autism CARES Act (previous full committee meeting in July 2014).
- New committee chair (Dr. Bruce Cuthbert, Acting Director, NIMH) and several new members including three self-advocates (roster at https://iacc.hhs.gov/)
- Primary focus of this meeting was to discuss approaches for developing the IACC Summary of Advances for 2014 and 2015 as well as updating the Strategic Plan; no decisions were made during the meeting but all comments and suggestions will be pulled together for review by the committee in the coming weeks
- Written and oral public comments were heard. Although there were concerns voiced about vaccines and autism, the predominant message was frustration and even despair at the lack of options for services for families particularly those with adult children who have more severe problems and cannot function independently
- All committee members were given the opportunity to provide a short update from their organizations; there will be opportunities for more extensive updates or presentations during future meetings
- Next IACC meeting will be January 12, 2016

Cynthia A. Moore, M.D., Ph.D.
Director
Division of Birth Defects and Developmental Disabilities
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Centers for Disease Control and Prevention
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Atlanta, GA 30341
(404) 498-3927 Direct line
(b)(6) Cell

(404) 498-3550 Fax
cmoore1@cdc.gov or cam0@cdc.gov

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 21 Oct 2014 13:50:02 +0000
To: Kipreos, Victoria (CDC/ONDIEH/NCBDDD); Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: email address

We need to have an anonymous email address set up for requesters of the MMR – autism dataset. Could one of you help with this. Andy: A head up – there will be a few requests coming into the box. Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

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From: Chaney, Sascha (CDC/ONDIEH/NCBDDD)
Sent: Thu, 19 May 2016 15:04:37 -0400
To: Harden, Camille (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Fwd: fyi

FYI

Get Outlook for iOS

From: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>
Sent: Thursday, May 19, 2016 2:47 PM
Subject: fyi
To: Weinbaum, Cindy (CDC/OID/NCEZID) <chw4@cdc.gov>, Pope, Kristin (CDC/OID/NCIRD) <kfp7@cdc.gov>, Chaney, Sascha (CDC/ONDIEH/NCBDDD) <zpo7@cdc.gov>, Levine, Nancy H. (CDC/OID/NCEZID) <ndl0@cdc.gov>

FinalCall.com
Wednesday, May 18, 2016

Town Hall Meeting Opens Eyes To Alleged CDC Cover-Up

By James G. Muhammad
-Contributing Editor-

CHICAGO--Tears streamed down the cheeks of Maisha Muhammad as she spoke of her son Elijah, who started to exhibit signs of autism around his second birthday.

The infant had been doing so well, she told an audience May 7 at Mosque Maryam at the National Center, headquarters of the Nation of Islam. He had started walking at six months. The closer he got to two years of age he stopped responding to his name, she said haltingly. He stopped trying to talk. He would lay in his crib silent for hours

"He was a shell of the beautiful child I once adored. This has been my reality for the last 16 years," she sobbed. "I have been looking for answers all of this time."

Mothers and fathers like Maisha found answers on this cool night on the South Side of Chicago. They had come to the mosque to view a controversial documentary, "Vaxxed: From Cover-Up to Catastrophe," which examines the link between the development of autism in infants who receive the Mumps, Measles and Rubella (MMR) vaccine during the prescribed 12 to 18 months of age. The significant thing that happened to Elijah prior to his second birthday is he received the MMR vaccine.

The film has caused tremors in the medical community, particularly since it documents an alleged cover-up of evidence that Black boys who receive the vaccine at the prescribed age developed autism at an alarming rate.

That data was purposely excluded from the final 2004 published study by CDC scientists, according to the film, and was only revealed a decade later by study co-author and CDC scientist Dr. William Thompson, who has since gained whistleblower protection status from the federal government.

Dr. Thompson has expressed a desire to be subpoenaed to testify before Congress about his allegations, but legislators appear to be afraid to touch the issue.

On hand for the screening were Dr. Brian Hooker and Del Bigtree. Dr. Hooker is a scientist who Dr. Thompson confided in about the cover-up and who also examined the original findings of the study. Bigtree produced the film.

Both men said the purpose of the film is to reveal the cover-up and to warn the community of the raised levels of autism in Black boys. They suggested that vaccines should be given at an older age, if a parent chooses to vaccinate a child, and that measles, mumps and rubella vaccinations should be given in single doses rather than the three in one MMR vaccination.

However, "12 to 18 months is actually the most dangerous time for African American boys to receive MMR," Mr. Bigtree said.

They also participated in a town hall discussion following the screening along with panelist Los Angeles-based Student Minister Tony Muhammad, Western Regional Representative of the Nation of Islam.

The story unfolds through the experiences of four main characters, Dr. Hooker, Mr. Bigtree, Dr. Andrew Wakefield, a British scientist who opened the door to the question of a relationship between the MMR vaccine and autism who directed the film, and Dr. Thompson, who is not seen on screen but his voice and words play a critical role in exposing the evidence of the alleged cover-up.

The film opens with television news clips of reporters blaring news about a 2014 measles outbreak in the U.S. and calls by celebrities and authorities for more vaccinations. Spokespersons also are shown debunking the notion that vaccines cause autism.

It is peppered with testimonies and anecdotes from other scientists and medical officials, as well as heart breaking stories from parents whose children went from being normal to being non-attentive, seemingly lifeless versions of their former selves.

A White mother talks about sitting in bed at nights with her husband and listening to the "thud, thud, thud" of her child banging his head against a wall.

A Black mother talks about taking her twin infants to the doctor and seeing six needles in a tray. Her daughter gets a shot but becomes

unsettled and while the mom is attending to her, the nurse gives her son a shot. Ultimately, the girl didn't get the MMR shot but the boy did and became autistic.

Years later the girl became fluent in three languages, is an A student and plays classical piano. The boy has serious developmental issues.

"With all of the guilt I feel from that day, one of the best decisions I made for [my daughter] was to walk out of that office and not let her be vaccinated," the mom says.

Many of the parents in the film became autism advocates, going on media shows and even starting their own publications to draw attention to the issue.

Dr. Wakefield first raised the question about the relationship between autism and vaccines after studying a 1987 outbreak of meningitis in infants who received the MMR vaccine in Canada. The vaccine was then banned in Canada but began being used in Europe until it was banned there. It then was shipped to Africa and other developing countries where outbreaks of meningitis soon followed.

Dr. Wakefield eventually was discredited in the medical community because of his unyielding aggressiveness to get the vaccine-autism issue investigated.

"The CDC doesn't study vaccines proactively," Dr. Hooker says on the film. "If Wakefield had never done his original study published in Lancet (medical journal), we would have never created the uproar it created and the CDC would have never studied this."

Dr. Hooker, whose 18-year-old son is autistic, became involved when he got a phone call from Dr. Thompson. Dr. Hooker recorded the calls as the CDC scientist guided him through the process of how to legally acquire a "treasure trove" of CDC documents that Dr. Thompson could not legally release.

According to the film, scientists working on a study must agree on an analysis plan to report their findings. In this case, CDC scientists deviated from the analysis plan in order to produce results that reduce the autism effect on Black boys.

"I have waited a long time to tell this story," says a voice reading Dr. Thompson's words. "We can't be trusted to be transparent. The CDC can't be trusted to police itself."

A former Merck pharmaceuticals sales representative reveals how the company manipulated data that hid evidence that the drug Vioxx elevated the risk of heart attacks and strokes. "What I learned from that experience is just because something is on the market it doesn't mean it's safe," she says.

The gold standard test for pharmaceutical drugs, according to the film, is a double blind, placebo-based, long term study which isn't done with vaccines because of the way they are classified. Also, vaccines aren't tested in combination with other vaccines, yet doctors can give two or more vaccines per visit.

The film also shows the power of big pharmaceutical companies that pushed Congress to pass laws that prevent them from being sued for injuries to people who use their drugs. Instead, victims must appeal to "Vaccine Courts" for redress, where the pharmaceutical companies do not have to participate.

Mr. Bigtree, a journalist affiliated with "The Doctors" television show, said the original MMR study was to last seven months but ended up taking several years because of the secret meetings where scientists discussed how to reveal the findings in a way to hide the impact on Black boys.

The film closes with Mr. Bigtree asking Dr. Rachel Ross of the "The Doctors" what she would do the next time a parent asks if a child should get the MMR vaccine.

"I will tell her, honestly I'm not going to give the MMR vaccine to my babies and here's why," she replies.

As the credits rolled down the screen at the end of the film, a long line was forming with people wanting to ask questions in a conversation that would be moderated by radio talk show host Cliff Kelley of WVON 1690AM.

Relating the CDC plan to scripture and the plans of King Herod and Pharaoh of Egypt to destroy Black boys, Student Minister Ishmael Muhammad, National Assistant to the Honorable Minister Louis Farrakhan told the crowd, "That was a painful documentary to watch, to know that every seven minutes a child is being diagnosed with autism. The plan is to cull the population by two to three million," he said. "This is not some conspiracy theory or reckless paranoia. This is actually happening. This story has to be told, whatever it takes to put this out."

Student Min. Tony Muhammad said Minister Farrakhan asked him to talk to U.S. Congressman Elijah Cummings (D-Md.) who heads the congressional

committee that oversees the CDC. The Nation of Islam, through Min. Farrakhan's call, has been instrumental in rallying the Black community to protest at CDC headquarters in Atlanta, drawing national attention to the issue.

Student Minister Tony Muhammad said the congressman initially was motivated to look into the whistleblower issue, but returned "with a cracking and trembling" in his voice saying only that he supports vaccines.

When the Nation of Islam Student Minister pushed him on the issue of calling the whistleblower before Congress because he had to report back to Min. Farrakhan, the congressman said, "Then do what you got to do. I'm not touching it, and hung up," he said.

The high energy of the meeting didn't die as people filed out of the mosque.

Patricia Withers, who is White and is a member of the Illinois Vaccine

Awareness Coalition, said she heard about the event through a community newspaper. The autism community has been energized by having the Black community involved, she said.

"The energy of this space and your (N.O.I.) community is healing to my heart," she said. "I didn't know much about the Nation of Islam but I feel welcomed and very connected. I feel on fire."

Khafre Watkins of nearby Des Plaines said it didn't make sense that people had to take so many vaccines, but he had no idea that some populations could be targeted whether intentionally or accidentally. He is suspicious about the relationship between insurance companies and pharmaceutical companies.

"There's a vicious circle of companies involved in this," he said. "That must be explored as well."

Dolphn Norris said the meeting "was a wakeup call. It's time for us to do a detox."

"This confirmed a lot for me about why a lot of our young men are killing each other. They're the babies that have been vaccinated and now they're 18 and 19 years old and their minds are all messed up," he said.

Miranda (Randy) Katsoyannis
CDC Washington Office
202-245-0600
www.cdc.gov/washington

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 6 Nov 2014 23:08:37 +0000
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: Fwd: MMR and autism

Vying

Sent from my iPad

Begin forwarded message:

From: "Destefano, Frank (CDC/OID/NCEZID)" <fxd1@cdc.gov>
Date: November 6, 2014 at 1:47:17 PM EST
To: "Gonzalez, Belsie (CDC/OD/OADC)" <fqi1@cdc.gov>
Cc: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Subject: FW: MMR and autism

Hi Belsie,
This is a message from a UK colleague. This is the first I've heard about a possible BMJ article and don't know anything more about it. We may have to be prepared to respond, but most of the communication staff here is tied up with Ebola.
Frank

From: Liz Miller [mailto:(b)(6)
Sent: Thursday, November 06, 2014 1:28 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: MMR and autism

Dear Frank

You may remember me from the MMR and autism days. The issue has resurfaced again in the UK as Brian Deer a journalist who exposed Wakefield's inappropriate conduct with respect to his Lancet study has now written an article for BMJ about the CDC study and the recent issues about the subgroup analysis in Afro Americans. He has spoken to Brian Hooker so not sure what line Deer will take. We have taken the line that the article by Hooker has been withdrawn and that CDC stands by its original analysis which we will reiterate but wondered whether you have any plans afoot to do any re-analyses or take the issue further. Is it the case that there will be a congressional review again on this?

Anyway we need to be prepared should this issue resurface and generate media interest again in the UK so any background you can give us would be helpful.

With best wishes

Liz

Professor Elizabeth Miller
Immunisation Hepatitis and Blood Safety Department
Public Health England
61, Colindale Avenue NW9 5EQ
London, UK
Direct line (b)(6)
Mobile (b)(6)

From: cab3@cdc.gov
Sent: Wed, 9 Dec 2015 18:26:29 -0500
To: (b)(6)
Subject: Fwd: rally rumors -- December 18

Sent from my iPad

Begin forwarded message:

From: "Chaney, Sascha (CDC/ONDIEH/NCEH)" <zpo7@cdc.gov>
Date: December 9, 2015 at 12:44:30 PM EST
To: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>, "Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)" <smd3@cdc.gov>
Subject: FW: rally rumors -- December 18

FYI

From: Waters, Tinsley (CDC/OD/OCS)
Sent: Wednesday, December 09, 2015 12:42 PM
To: Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>
Subject: FW: rally rumors -- December 18

Hi Sascha,

Just got this note from OADC—sending as FYI and will let you know if we learn more. Please do the same—

Thanks,
Tinsley

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Wednesday, December 09, 2015 12:37 PM
To: Waters, Tinsley (CDC/OD/OCS)
Subject: rally rumors -- December 18

Tinsley,

I learned that Curtis Duncan (blogger) is promoting a rally about vaccines and autism to take place on Friday 12/18/15 from 7:00 AM to 2:00 PM in front of the Roybal Campus. I did a google search to see if there is anything about it anywhere else and I only found a two posts from Mr. Duncan on his FB page, and a local non-for-profit that had the same announcement, www.cdctruthatl.org.

I alerted security and OADC leadership. I'll continue providing information as the date approaches, but the lack of information in the internet might represent lack of support.

The same morning, four journalists from a public broadcast agency, NHK, in Japan are scheduled to come to CDC to do interviews about vaccine safety

Regards,

Belsie

Belsie González, MPH
Senior Public Affairs Specialist | Centers for Disease Control and Prevention |
bgonzalez2@cdc.gov | office: (404) 639-0668 | media@cdc.gov

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 22 Mar 2016 22:03:06 +0000
To: Ikeda, Robin (CDC/ONDIEH/OD)
Subject: FW: Anti CDC film in Tribeca Film Festival

FYI

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
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Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Alison Singer [mailto:(b)(6)@autismsciencefoundation.org]
Sent: Tuesday, March 22, 2016 3:19 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: Anti CDC film in Tribeca Film Festival

Andrew Wakefield's movie claiming a cover up of a vaccine/autism link by the CDC will be premiering in April at the Tribeca film festival. Link: http://vaxxedthemovie.com

Details:

"Vaxxed: From Cover-Up to Catastrophe
The most vitriolic debate in medical history takes a dramatic turn when senior scientist turned whistleblower, Dr. William Thompson of the Centers for Disease Control, turns over secret documents, data, and internal emails confirming what millions of devastated parents and "discredited" doctors have long-suspected—vaccines do cause autism.
After the movie: A conversation with creators and subjects of the film.
DATE: Sunday, April 24

TIME: 2:00 p.m.
LOCATION: SVA2"

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Alison Singer
President
Autism Science Foundation
(b)(6)
106 West 32nd Street, #182
New York, NY 10001

From: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Sent: Fri, 19 Sep 2014 13:34:54 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: BMJ request for documents

-----Original Message-----
From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, September 19, 2014 12:57 PM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Cc: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: BMJ request for documents

Hi Sal -

This guy is not requesting the data per se. He's requesting all of our internal documents related to the study, which I don't have (several people have their own records) and wouldn't give out if requested (other than a FOIA). I can give him the data, after he sends in a proposal to be evaluated, but the other stuff is not available. Can you please respond to him? And copy me? Thanks!

Andrew R. Autry, PhD
IT Project Manager
CDC/NCBDDD
1600 Clifton Road, MS E-87
Atlanta GA 30329
404-498-3876 (office)
(b)(6)

I telework on Fridays and can be reached at (b)(6) Overnight address: 1825 Century Center Parkway
Atlanta GA 30345

-----Original Message-----
From: Peter Doshi [mailto:(b)(6) @bmj.com]
Sent: Friday, September 05, 2014 11:05 AM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: BMJ request for documents

Dear Dr. Autry,

The BMJ is interested in obtaining documents related to statements made by Dr. William W. Thompson concerning the 2004 DeStefano et al. paper on MMR and autism (Pediatrics 2004;113:259-266).

I am contacting you because you are listed as the contact for access to the dataset used by DeStefano et al..
http://www.cdc.gov/vaccinesafety/Concerns/Autism/cdc2004pediatrics.html and
http://www.cdc.gov/ncbddd/developmentaldisabilities/maddsp-data-sets.html

I am interested in obtaining access to copies of various original documents separate from the dataset including:

- original study protocol

- protocol amendments
- final study protocol
- pre-publication drafts of the DeStefano manuscript
- memos discussing the study
- any other documents that help understand how the study was conducted, analyzed, and reported.

Can you help provide us with any/all of the above? If not, could you tell me how I might go about obtaining these documents?

Best regards,
Peter Doshi

Peter Doshi
Associate Editor, The BMJ
220 Arch Street, Floor 12
Baltimore, MD 21201, U.S.A.
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From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 2 Oct 2014 19:43:42 +0000
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: FW: BMJ request re William Thompson
Attachments: MMR_analysis_plan_FINAL.PDF

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
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Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, October 02, 2014 3:21 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: BMJ request re William Thompson

The analysis plan was provided to BMJ.

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Thursday, October 02, 2014 1:18 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: FW: BMJ request re William Thompson

Here you go.

From: Brower, Melissa (CDC/OID/NCEZID)
Sent: Thursday, October 02, 2014 1:02 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Gonzalez, Belsie (CDC/OD/OADC)

Cc: Coffin, Nicole (CDC/OID/NCEZID)
Subject: RE: BMJ request re William Thompson

Yes—at this point, we've just provided the analysis plan (attached).

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Thursday, October 02, 2014 1:00 PM
To: Brower, Melissa (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Coffin, Nicole (CDC/OID/NCEZID)
Subject: RE: BMJ request re William Thompson

Hi there. Can we find out what materials he has access to – or has been provided by CDC? Frank would like to see these materials before providing a response to his questions.

-Angela

From: Brower, Melissa (CDC/OID/NCEZID)
Sent: Thursday, October 02, 2014 12:26 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Coffin, Nicole (CDC/OID/NCEZID)
Subject: RE: BMJ request re William Thompson

Thanks—can you work with Frank to see if we're able to answer any of these questions?

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Thursday, October 02, 2014 12:19 PM
To: Gonzalez, Belsie (CDC/OD/OADC); Brower, Melissa (CDC/OID/NCEZID)
Cc: Coffin, Nicole (CDC/OID/NCEZID)
Subject: FW: BMJ request re William Thompson

Hi there. I'm forwarding to you ladies for you to respond to the direct inquiry from BMJ to Dr. DeStefano. Thanks.

-Angela

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, October 02, 2014 12:17 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Subject: FW: BMJ request re William Thompson

Angela,
I am forwarding this to you, but I realize that this will probably have to go to CDC OD communication in terms of how to respond. I'm just not sure who this should go to.
Thanks,
Frank

From: Rebecca Coombes [mailto:(b)(6) @bmj.com]
Sent: Thursday, October 02, 2014 11:51 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: BMJ request re William Thompson

Dear Dr. DeStefano,

We at *The BMJ* were interested in recent statements made by William Thompson concerning a paper you co-authored with him in 2004 on MMR and autism (Pediatrics 2004;113:259–266).

For reference, Dr. Thompson's statements are here:
http://www.morganverkamp.com/august-27-2014-press-release-statement-of-william-w-thompson-ph-d-regarding-the-2004-article-examining-the-possibility-of-a-relationship-between-mmr-vaccine-and-autism/

One of the statements Dr. Thompson makes is: "I regret that my coauthors and I omitted statistically significant information in our 2004 article published in the journal Pediatrics. The omitted data suggested that African American males who received the MMR vaccine before age 36 months were at increased risk for autism. Decisions were made regarding which findings to report after the data were collected, and I believe that the final study protocol was not followed."

I am trying to look into the matter to substantiate some of the claims. I have obtained a copy of the final study protocol from CDC.

Based on my reading of the materials, I have the following questions I was hoping you could answer:

1. Why did you not do an analysis by race for the full study population despite having the data and indicating this would be done in the final study protocol?

2. What would the results by race look like for the full study cohort?

3. Prior to publication of the manuscript, did you have results that "suggested that African American males who received the MMR vaccine before age 36 months were at increased risk for autism", as Dr. Thompson says?

May I have your response by 5:00 PM EST on Monday?

Thank you for your help.

Rebecca Coombes
Magazine Editor
BMJ

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Twitter: @rebeccacoombes

Autism and Childhood MMR Vaccine
Draft of Analysis Plan

September 5, 2001

Introduction

Autism is a serious life-long developmental disorder characterized by marked impairments in social interactions, and communication skills; and repetitive, restrictive, or stereotyped behaviors. A recent review of studies conducted since 1985, shows an estimate of the prevalence to be 1-1.4 per 1,000 for classic autism, and possibly as high as 4-5 per 1,000 for all autism spectrum disorders (ASD) combined (Kedesjo et al 1999; Rapin, 1997; Arvidsson et al., 1997). While these rates are 3-4 times higher than rates found in studies conducted 15-20 years ago (Fombonne, 1999), there are several recent studies, including a study done by Baird et al. (2000) and an investigation in Brick Township NJ, which suggested that the rate of autism may be higher still with rates of 3.1 per 1,000 and 4 per 1,000 respectively (CDC 2000; Baird et al. 2000). These higher prevalence rates, coupled with reports of increasing numbers of children with autism being served by schools and service agencies (California Department of Developmental Services,1999) have prompted concerns that the rate of autism may be increasing.

A study published in 1998 in the Lancet (Wakefield et al, 1998) has lead some to hypothesize the MMR vaccine may play a role in the recent trend upward in autism rates. This study was a case series of 12 children who were referred to a pediatric gastroenterology clinic because of chronic enterocolitis and were found to also have autistic behavioral characteristics. Eight of the 12 children were reported by parental interview as first experiencing the onset of autistic-like symptoms following the MMR vaccine, and an additional child's onset occurred after measles infection which lead the investigators to hypothesize that the measles, mumps and rubella vaccine might be associated with the onset of autism. While suggestive, this clinical case study lacked evidence to evaluate a possible causal association between MMR vaccine and the occurrence of ASD (6). More recently, Wakefield and Montgomery (1999) have suggested that the MMR vaccine may alter the immune response for one of the vaccine components due to an interaction with one or more of the other vaccine components. Animal models support the possibility of interference of T-cell responses based on exposure to several viruses simultaneously but to date this has not been demonstrated with the MMR vaccine (IOM, 2001). Wakefield et al., (1998, 2000) have also suggested that exposure to the MMR vaccine may be linked to inflammation-mediated intestinal permeability that results in incomplete breakdown and excessive absorption of gut-derived peptides from certain foods (Wakefield, 2001).

A number of other studies have been designed to try and confirm the alleged association found between autism and the MMR vaccine. A study in Sweden, which used data from the only ongoing population-based registry of autism, showed that the prevalence of autism did not increase after the introduction of the MMR vaccine in 1982. (Gillberg & Heijbel, 1998).

Taylor et al. (1999) identified 498 children with autism (261 with typical autism, 166 with atypical autism, and 71 with Asperger's syndrome) in eight North Thames health districts in the

United Kingdom (UK) who were born since 1979. These cases were linked to an independent regional vaccination registry. The investigators examined time trends in rates of autism, compared age at diagnosis for children vaccinated before and after 18 months of age, and performed a case series analyses examining temporal trends between MMR vaccination and age of onset of autism. There were no statistically significant associations between the onset of autism within 1 or 2 years after vaccination with MMR. Further, developmental regression was not clustered in the months following vaccination and no significant temporal clustering for age at onset of parental concern was seen for cases of core autism or atypical autism with the exception of a single interval within 6 months of MMR vaccination. There were several possible weaknesses in the study including failure to confirm ICD10 criteria for diagnosis of ASD and the possibility of incomplete ascertainment.

In a series of large epidemiology studies (Patja A, Davidkin I, Kurki et al, 2000; Peltola H, Patja A, Leinikki P., 1998) a Finnish cohort of 1.8 million individuals with approximately 3 million MMR vaccine doses from 1982 to 1996 was examined. There were 173 potentially serious adverse events that were claimed to be causally associated with MMR vaccination. Of these adverse events, 45% had evidence suggesting other causes or contributing factors (i.e, infectious agents, viruses). The resulting incidence of adverse events was 5.3 per 100,000 MMR vaccinees. There were no cases of autism that were associated with MMR vaccination.

In 2001, Kaye et al. (2001) published a study that examined children 12 years of age or younger from the UK diagnosed with autism between 1988 and 1999 through the use of the UK general practice research database. Because only 3% of children did not receive the MMR vaccine, time trend analyses were carried out to determine whether there was a temporal association between the age of receipt of the MMR vaccine and the diagnosis of autism over time. A total of 305 children with autism aged 12 years or younger whose first recorded diagnosis occurred between 1988 and 1999 were identified from 3,092,742 person year observations. Subsequent analyses were restricted to boys aged 2 to 5 years born between 1988 and 1993. Annual birth cohorts were analyzed separately. There was a significant increase in the rates of autism between 1988 and 1999 from 0.3 per 10,000 person years in 1988 to 2.1 per 10,000 person years in 1999. However, there was no temporal association between MMR prevalence rates and the risk for autism. The major weakness in the study was that diagnosis of autism was not confirmed from original records.

More recently, Dale et al. (2001) published results of a study carried out in California that was conducted to determine if a correlation existed between the trends of MMR vaccine coverage and autism occurrence. The researchers of this study performed retrospective analyses of children from kindergartens who were born in 1980 to 1994 (samples of 600-1900 children each year) and of autism cases derived from the California Department of Developmental Services who were born in the same years. School immunization records were reviewed to determine the age at which children received the first dose of the MMR vaccination. Two main outcome measures were used: the proportion of children in each birth year that received the MMR vaccine by the age of 17 months and the proportion of children that received the vaccine by the age of 24 months. The results of this study showed no correlation between the trend in MMR vaccine coverage and the occurrence of autism. It was noted that there was a marked increase in autism from 1980 to 1994, 44 per 100.000 in 1980 to 208 per 100,000 in 1994; however, it was also

found that changes in MMR immunization coverage were smaller and of shorter duration. The administrative data had limitations especially with the diagnosis of autism.

Finally, in April of this year the Institute of Medicine (2001) reviewed the research examining the association between the receipt of the MMR vaccine and risk for autism. They concluded "The evidence favors the rejection of a causal relationship at the population level between MMR vaccine and autistic spectrum disorder." Although they rejected a causal hypothesis at the population level they strongly encouraged additional studies to examine possible associations between the MMR and certain subgroups of autistic children.

In terms of the suggested link between MMR vaccination, inflammatory bowel disease (IBD) and autism (Wakefield et al.1998, 2000, 2001) several additional studies have been carried out to try and confirm the associations. Fombonne (1998) using two large databases (a clinical database from the Child and Adolescent Psychiatry Services of large teaching hospital in south London with about 9000 clinic records and a second survey of autism in France in school-aged children in three French departments from a population of 325,347 children) examined records of children with autism for the co-occurrence of ulcerative colitis or Crohn's disease. There were no cases that were identified in either database, suggesting that if the two conditions were associated, as suggested by Wakefield et al. (1998) it was a rare occurrence.

Davis, Kramarz, Bohlke et al (2001) carried out a case-control study of individuals from four large health maintenance organizations in the United States. They identified 155 cases with ICD-9 codes for IBD and up to 5 controls matched on sex, age, and HMO. Only 142 cases were subsequently used in the analyses of timing of vaccination and diagnosis of IBD. Of the 142 cases, 75 were Crohn's diseases and 67 had ulcerative colitis (UC). Ninety four (66%) of cases had been vaccinated with MMR and 38 with other measles containing vaccines (MCV). Ten had never been vaccinated with either MMR or MCV. There were no statistical associations between timing of vaccination and subsequent diagnosis of IBD, Crohn's Diseases or UC at 2, 4, 6, or 12 months after vaccination.

In an effort to resolve the speculation regarding the association between the MMR vaccine and autism, investigators from the CDC have conducted a matched case-control study utilizing the Metropolitan Atlanta Developmental Disabilities Surveillance Program to look at this potential relationship. The main objective of this study is to evaluate the association between the CDC case definition for autism and timing of the receipt of the MMR vaccine.

The CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) monitors the rate of serious developmental disabilities using records from public school special education and other medical facilities for children with one or more of four developmental disabilities -- mental retardation, cerebral palsy, hearing impairment, and vision impairment. In the 1996 surveillance year autism was added to the MADDSP in response to public concern about the possible increase in the prevalence of autism and related disorders. The first year of prevalence data for autism is completed with over 700 children with autism identified. The strengths of MADDSP include the multiple source approach to identifying children with developmental disabilities and the expert clinical review of case information to determine cases status.

Justification for Study

Several limitations of previous investigations examining the association between the MMR vaccine and autism included incomplete case ascertainment and inability to confirm the diagnosis of autism. Most of the studies described above used selected service provider databases to identify children with autism and only the Taylor et al. (1999) study attempted to confirm the diagnosis of autism from original records. These limitations along with the continuing concern surrounding this issue suggested the need for further research to clarify the relationship between MMR vaccine and autism. The benefits of the CDC study include 1) complete ascertainment of known cases from a large population, 2) extensive record review of cases by a panel of autism experts to confirm the case definition for autism, 3) inclusion of a sample of controls matched by age, sex, and school system to compare the distribution of age at MMR vaccination among cases and controls, 4) inclusion of birth records to control for other background variables that may be associated with autism and receipt of MMR vaccine including birth weight, gestational age, maternal age, and maternal education, and 5) because of the extensive clinical information on case children, the ability to examine the case group by the presence or absence of other co-existing conditions, e.g. mental retardation and possible genetic risk factors. It is expected that findings from this study will provide important information regarding the relationship between MMR vaccine and autism.

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From: Chaney, Sascha (CDC/ONDIEH/NCEH)
Sent: Mon, 2 Nov 2015 11:06:05 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Subject: Fw: CDC Vaccine Coverup Story

Fyi

From: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>
Sent: Monday, November 2, 2015 10:55 AM
To: Pope, Kristin (CDC/OID/NCIRD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Weinbaum, Cindy (CDC/OID/NCEZID); Levine, Nancy H. (CDC/OID/NCEZID); Chaney, Sascha (CDC/ONDIEH/NCEH); Ghosh, Sudevi (CDC/OCOO/OGC)
Subject: FW: CDC Vaccine Coverup Story

fyi

From: Beavin, Shana (CDC/OD/CDCWO)
Sent: Monday, November 02, 2015 10:46 AM
To: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>
Subject: CDC Vaccine Coverup Story

Saw this on my facebook page of all places from a friend in FL:

http://ecowatch.com/2015/11/01/cdc-vaccine-cover-up-autism/

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Mon, 3 Aug 2015 13:23:45 +0000
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: FW: Comment on Thompson "garbage can" quote from Rep Posey?

FYI –

From: Emily Willingham [mailto:(b)(6)@gmail.com]
Sent: Sunday, August 02, 2015 6:56 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: Comment on Thompson "garbage can" quote from Rep Posey?

Dear Dr. Boyle:

I'm sure you're aware of the "whistleblower" situation involving your co-author William Thompson. I am a contributor at Forbes who writes frequently about autism (and, by necessity, therefore, about autism and vaccines), and I was wondering if you could comment on this latest material that Congressman Bill Posey has attributed to Thompson:

At the bottom of Table 7 it also shows that for the non-birth certificate sample, the adjusted race effect statistical significance was huge. All the authors and I met and decided sometime between August and September '02 not to report any race effects for the paper. Sometime soon after the meeting, we decided to exclude reporting any race effects, the co-authors scheduled a meeting to destroy documents related to the study. The remaining four co-authors all met and brought a big garbage can into the meeting room and reviewed and went through all the hard copy documents that we had thought we should discard and put them in a huge garbage can. However, because I assumed it was illegal and would violate both FOIA and DOJ requests, I kept hard copies of all documents in my office and I retained all associated computer files. I believe we intentionally withheld controversial findings from the final draft of the Pediatrics paper.

I infer that trashcan or no trashcan, many digital versions of these data, which were derived from existing databases, remained available for record-keeping. Would you be able to confirm that?

Thus far, this story has had zero balance regarding Thompson's statements or representations of his statements. I would, at the least, like to be able to provide an on-the-record version of what is described above ... even if it's attributed only to "one of the paper authors who was there." Any counterpoint and/or confirmation you can provide would be helpful. I am reaching out to all of the authors on the paper with this query.

Thank you for your time.

Best,
Emily Willingham
(b)(6)

Emily Willingham, PhD
Science Writer and Editor

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Wed, 3 Sep 2014 11:14:50 -0400
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: FW: DeStefano et al, study protocol request

-----Original Message-----
From: Brower, Melissa (CDC/OID/NCEZID)
Sent: Wednesday, September 03, 2014 10:07 AM
To: Weinbaum, Cindy (CDC/OID/NCEZID); Destefano, Frank (CDC/OID/NCEZID)
Cc: Coffin, Nicole (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: FW: DeStefano et al, study protocol request

Hi guys,

Please see the request below from Brian Deer. Is this something we can provide? (Belsie, not sure if you're familiar with Brian: http://briandeer.com/mmr-lancet.htm.)

Thanks!

Melissa

-----Original Message-----
From: Brian Deer [mailto:(b)(6) @briandeer.com]
Sent: Wednesday, September 03, 2014 9:37 AM
To: Brower, Melissa (CDC/OID/NCEZID)
Subject: DeStefano et al, study protocol request

Hi Melissa,

Thanks for keeping me updated, and for setting up the very helpful conversation with Dr DeStefano.

I've discussed the issue with Dr Fiona Godlee, editor of the BMJ, the British Medical Journal, who has suggested that I look further into this. Her specialism is clinical evidence, and so she's fascinated by the debate around the 2004 Pediatrics paper.

Would it be possible for me to obtain a copy of the trial protocol for the project, and any amendments to that? I know this is a public document, but where exactly a PDF of it might be is beyond my thoughts to make a suggestion.

Once I've read that, maybe I could come back to you with any further queries. Unlike most journalists, I have a bit of time to get my facts right and to put the whole thing in the right context, and I'm sure that a sensitive exposition will be helpful to other media, who may find a briefing in a high-impact medical journal a great time-saver.

With best wishes,

Brian

At 18:06 25/08/2014 +0000, you wrote:
>Hi again,
>
>Just wanted to let you know that we decided to post a statement on our
>vaccine safety website, here:
>http://www.cdc.gov/vaccinesafety/Concerns/Autism/cdc2004pediatrics.html.
>Please just let me know if you have any questions or need anything else.
>
>Best,
>
>Melissa
>
>
>-----Original Message-----
>From: Brian Deer [mailto:(b)(6)@briandeer.com]
>Sent: Friday, August 22, 2014 9:53 AM
>To: Brower, Melissa (CDC/OID/NCEZID)
>Subject: Re: Request for comment from CDC
>
>Of course.
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>
>
>At 13:51 22/08/2014 +0000, you wrote:
> >Thanks! Would it be possible to push this back 15 minutes? Dr.
> >DeStefano will be coming back to his office from a meeting and may
> >run a few minutes late.
> >
> >Best,
> >
> >Melissa
> >
> >
> >----- Original Message -----
> >From: Brian Deer [mailto:(b)(6)@briandeer.com]
> >Sent: Friday, August 22, 2014 09:40 AM
> >To: Brower, Melissa (CDC/OID/NCEZID)
> >Subject: RE: Request for comment from CDC
> >
> >Hi Melissa,
> >
> >Just to say I'm on standy to chat with Dr DeStafano at 10.
> >
> >In case you lost it +(b)(6)
> >
> >Best wishes,
> >
> >Brian
>
>
>http://briandeer.com

http://briandeer.com

(b)(5)

(b)(5)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 9 Oct 2014 12:28:54 +0000
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Cc: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: Follow-up Regarding the 2004 Autism Paper

FYI – can someone send Dr. Kemper the protocol that was shared with the BMJ? Perhaps Belsie can do since I'm sure Barbara is very busy. Can we also let him know how to get access to the data as requested. I assume there is information on our website on this.

Thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Alex Kemper, M.D. [mailto:(b)(6)@duke.edu]
Sent: Thursday, October 09, 2014 8:25 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Follow-up Regarding the 2004 Autism Paper

Dr. Boyle,

I hope you are well.

I was hoping that you could email me a copy of the protocol used for the 2004 PEDIATRICS paper on MMR and autism. I requested the protocol from Dr. Reynolds, but have not heard back.

Also, as I understand it, the data used in that paper are publicly available upon request. Can you let me know what the process is to get access to those data?

Thanks,

Alex R. Kemper, MD, MPH, MS
Deputy Editor, PEDIATRICS

From: Chaney, Sascha (CDC/ONDIEH/NCEH)
Sent: Tue, 22 Mar 2016 14:35:54 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Fw: following up

From: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>
Sent: Tuesday, March 22, 2016 2:15 PM
To: Chaney, Sascha (CDC/ONDIEH/NCEH)
Cc: Nolan, Martha (CDC/OD/CDCWO)
Subject: following up

Hi Sascha,
Karyn indicated that a rumor is going around that the oversight committee is talking about an autism hearing.
To my knowledge, they are interested in the whistleblower case. We have briefed a subcommittee staff director, who is supportive of CDC, on vaccine safety issues. Tom Shimabukuro was the SME briefed. No mention of autism, but there was mention of outside constituents barraging members about the whistleblower case.
Let me know if you want to chat. If I had known this was an issue last week, I would have reached out to you.
Thanks,
Randy

Miranda (Randy) Katsoyannis
CDC Washington Office
202-245-0600
www.cdc.gov/washington

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 6 Jan 2016 23:29:22 +0000
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: FW: fyi - of interest

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, January 06, 2016 4:25 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: fyi - of interest

Assume you got this…..

From: Weinbaum, Cindy (CDC/OID/NCEZID)
Sent: Wednesday, January 06, 2016 12:09 PM
To: Levine, Nancy H. (CDC/OID/NCEZID) <ndl0@cdc.gov>
Subject: FW: fyi - of interest

Fyi, too.

From: Katsoyannis, Miranda (CDC/OD/CDCWO)
Sent: Wednesday, January 06, 2016 12:02 PM
To: Wharton, Melinda (CDC/OID/NCIRD) <mew2@cdc.gov>; Weinbaum, Cindy (CDC/OID/NCEZID)

<chw4@cdc.gov>; Pope, Kristin (CDC/OID/NCIRD) <kfp7@cdc.gov>; Ghosh, Sudevi (CDC/OCOO/OGC) <ggq4@cdc.gov>
Subject: fyi - of interest

Science Blogs

The CDC whistleblower documents: A whole lot of nothing and no conspiracy to hide an MMR-autism link


Posted by Orac on January 5, 2016

Obviously, this is how antivaccinationists look at vaccines, even though there is about 20 times the volume of a typical vaccine in that syringe, and vaccines generally aren't red. But the needle and syringe are big, the doctor looks menacing, and that's enough for the antivaccine movement. One of the stories dominating my blogging in 2015 was a manufactroversy that started in August 2014 when, after several months of rumbling in the antivaccine crankosphere that there was a CDC scientist ready to blow the whistle on an alleged coverup of evidence that vaccines cause autism, Andrew Wakefield, ever the publicity hog, released a video entitled CDC Whistleblower Revealed, in which he claimed that he had evidence of a "high level deception" of the American people about vaccine safety and revealed the "CDC Whistleblower" to be one William W. Thompson, PhD, a psychologist by training who worked for the CDC studying vaccine safety in epidemiological studies and who had had many telephone conversations with a biochemical engineer turned incompetent epidemiologist named Brian Hooker. Unbeknownst to Thompson, Hooker had been recording their conversations, and carefully cherry picked excerpts were included in the video, interspersed with Andrew Wakefield making hyperbolically offensive claims that this "coverup" was as bad as the Tuskegee syphilis experiment, with the CDC being worse than Hitler, Stalin, and Pol Pot. (I kid you not.) We now know that Thompson had been assisting Hooker in a "reanalysis" of a pivotal study of vaccine safety by DeStefano et al for which he had been co-author looking at whether the MMR vaccine was associated with autism in children in the Atlanta area. (Spoilers: It wasn't.) The reanalysis claimed to have found an increased risk of autism for a small subset: African American males who had been vaccinated before age 3. Of course, the study, even with Hooker's incompetent reanalysis, had failed to find a correlation in any other subgroup, leading me to refer to it as having proven Andrew Wakefield wrong.

Thus was born the saga of the "CDC whistleblower," a.k.a. William Thompson, which has dominated Twitter through the #CDCwhistleblower hashtag for over a year now. There's been a

major new development in this story that I just couldn't wait to tell you about: Matt Carrey now has the CDC whistleblower documents, and, as a result, so do I and so can you. Let me explain.

But first, let me note that Hooker's study was unbelievably incompetently done, with failure to control for some obvious key confounders, which is not surprising given Hooker's misplaced love of "simplicity" in statistical analysis; that, and the fact that he did a cohort study using data collected to do a case control study. Epic incompetence indeed, so much so that his study was ultimately retracted by the journal—and rightly so. Unfortunately, it had been the supposed "coverup" of the preliminary "positive" result in a small subset of the study population that didn't hold up when confounders were controlled for that had infuriated Thompson, who had felt dismissed and used. He's been silent since, but the events he set into motion fueled more paranoid conspiracy theories in the antivaccine movement, which led to its teaming up with the Nation of Islam, pulling Robert F. Kennedy, Jr. out from whatever rock he had been hiding under and dusting him off, and holding a protest at the CDC in October. Meanwhile Kevin Barry published a book of transcripts of four of Thompson's conversations with Hooker, which revealed a rather angry, troubled man out to strike out at his former CDC colleagues even though he still works at the CDC in another branch.

Right now, here's where the manufactroversy stands. Thompson provided Rep. Bill Posey (R-FL) with a bunch of documents that he claimed to have saved from being disposed of that "prove" that there was a coverup of unwanted results. One of his key claims was that the CDC changed the analysis plan after the study had started because the CDC didn't like the race results that implied a correlation between MMR vaccination and autism in African American boys, which is a definite no-no. He also accused them of destroying original documents. Posey called for an investigation in a little seen speech a couple of days before Congress left for its summer recess, resulting in a resounding yawn and no action. Ultimately, an opportunistic Alex Jones wannabe anchor of the Atlanta CBS affiliate, Ben Swann, acquired the documents from Posey in late November and promised to do a report on them. There has been no story yet, and now, thanks to Matt, I know why. There's nothing in those documents that support allegations of a coverup.

How did Matt acquire the documents? Let him explain:

Congressman Posey released the documents to a journalist recently and, given that they are now in the public domain, Dorit Reiss and I requested that they be made available to us as well. Mr. Posey's office graciously granted our request and I have spent some time going through them.

Matt has also made the documents available to several other bloggers, including me, and I thank him for that. I, too, have gone over the documents, albeit not every single one of them and not in as much detail as Matt. He has also made them available at a DropBox link for anyone out there who is curious and wants to read them. I warn you, though. It's very tedious reading, particularly various meeting agendas and the like, as well as SAS spreadsheets. In all, there are over 150 MB worth of scanned PDFs. However, there are most definitely not 100,000 documents there, as some antivaccine cranks have claimed. Matt says there are about 1,000 pages, and that seems about right to me, not having counted them all myself.

There are a few key points that arise from this document dump. First, there are multiple drafts of the analysis plan; that is, the protocol for collecting and analyzing the data that Hooker and Wakefield claim was changed after the first analysis of race data. They confirm what we already know, namely that the final analysis plan was dated September 5, 2001 and the first race analysis

didn't occur until October or November. But there's more than that. Matt found what appears to be the first draft of the analysis plan, complete with markup and notes in the margins:

Note that this draft analysis plan is from April 3, 2001. Well before the final version, the "protocol", which was September 5. More importantly, this is a long time before a race analysis was started. But even more, notice how there's an annotation "I would include race as a covariate, not as an exposure variable." That's critical–they decided against using race as an exposure variable from the start. Before they did a race analysis. Another point: they were already planning on using birth certificate data right from the start.

A word of explanation here. In his original video, Wakefield zeroed in on a single sentence that says "The only variable available to be assessed as a potential confounder using the entire sample is child's race." Based on that, and allegedly confirmed by Thompson during conversations with Hooker, Wakefield and Hooker claimed that "decisions were made regarding which findings to report after the data was collected," further claiming, "Thompson's conversations with Hooker confirmed that it was only after the CDC study coauthors observed results indicating a statistical association between MMR timing and autism among African-Americans boys, that they introduced the Georgia birth certificate criterion as a requirement for participation in the study. This had the effect of reducing the sample size by 41% and eliminating the statistical significance of the finding, which Hooker calls a direct deviation from the agreed upon final study protocol – a serious violation.'" Of course, the reason they did the birth certificate analysis is because it allowed them to "obtain additional information, such as each child's birth weight and gestational age and the mother's parity, age, race, and education." More importantly, as Matt discovered, the very first draft of the analysis plan indicated that the investigators were already planning on using birth certificate data. There was no change in protocol to "cover up" results the investigators found "inconvenient," namely the initial finding of a seeming correlation between a specific age range of MMR vaccination and autism in African American boys.

There's no way Thompson didn't know this, at least at the time he was working on this study with his collaborators. Perhaps he forgot. (I'm being charitable.) Of course, I'm not so charitable about Wakefield and Hooker, who also had all these documents. Surely they were poring over them with a fine-toothed comb for any dirt they could find, and in doing so they had to have read the early versions of the analysis plan. I also noticed, as did Matt, that Thompson annotated a number of the documents, in particular a file containing all the agendas for meetings on the study. It's impossible to know when he did this, whether it was contemporaneously or long after the fact, but it looks as though it was probably after, given how prominently some dates are circled. As Matt notes, it also looks as though Thompson was trying to make the data fit his story, rather than the other way around. His purple marker is all over the place the annotations in purple appear everywhere.

There are other things in these documents as well. For instance, there is this statement by William Thompson with a timeline of his version of events dated September 9, 2014. The funny thing is, even his own timeline doesn't really support the allegation being made by Hooker and Wakefield that the protocol was altered post hoc in order to "hide" the effect. Rather, he claims:

The final analysis plan described analyses for the TOTAL sample and the BIRTH CERTIFICATE sample which included assessment of the RACE variable. (See pages 7 and 8 of the Final Analysis Plan). There were two primary endpoints for the study. One was using a threshold of 36 months (see Table 3a of Final Analysis Plan), and the second was a threshold of 18 months. (See Table 3b of Final Analysis Plan). We hypothesized that if we found statistically

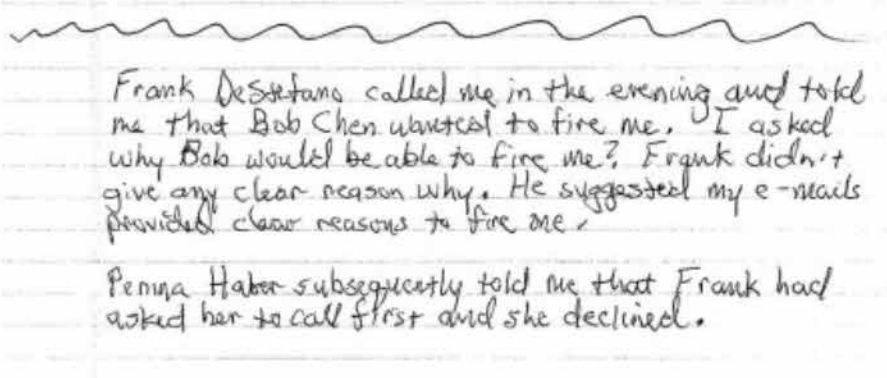
significant effects at either the 18-month or 36-month threshold, we would conclude that vaccinating children early with the MMR vaccine could lead to autism-like characteristics or features. We never claimed or intended that if we found statistically significant effects in the TOTAL SAMPLE, we would ignore the results if they could not be confirmed in the BIRTH CERTIFICATE SAMPLE.

I note that the protocol didn't mandate reporting effects whose statistical significance went away when tested in the birth certificate cohort, either. Whether or not to report spurious results that disappeared when a more confounders were accounted for would have been a matter of judgment more than anything else. We can argue whether it was good judgment to leave the preliminary result out as insignificant (more on that later), but it wasn't a violation of the protocol as far as I can tell. Also, as yet I haven't seen anything objective or contemporaneous that even hints at hiding data, destroying data, or otherwise manipulating data. Instead, there are plenty of comments about *including* things to avoid any appearance of willful omission. If this is a coverup, it's the worst coverup ever. None of that stopped William Thompson.

We also learn from these documents that Thompson was causing trouble resulting in his being in trouble. Matt was too circumspect to mention that, but I think it's important to mention in order (1) to show that Thompson has an axe to grind now and (2) because you know that when it comes out the cry from the antivaccine crankosphere will be that Thompson was being "persecuted." Thompson's description in his own words is in the timeline:

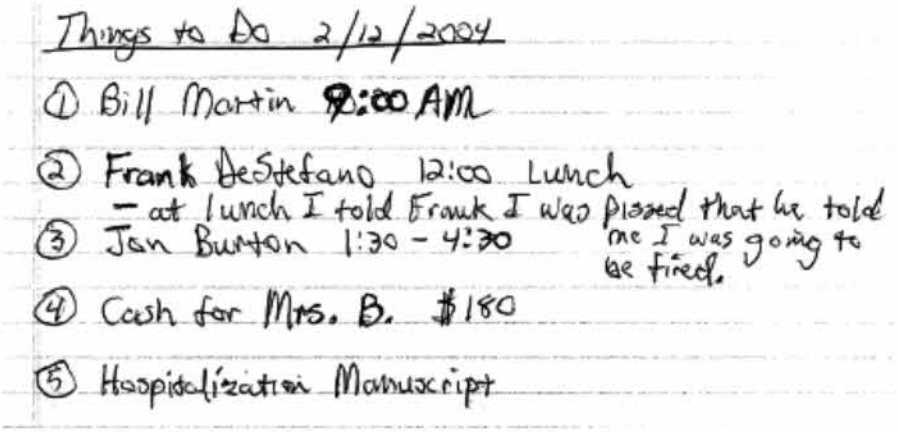
On March 9th, I was put on administrative leave. In the Annex to the memorandum, they provided a list of my "inappropriate and unacceptable behavior in the work place" which included "you criticized the NIP/OD for doing very poor job of representing vaccine safety issues, claimed that NIP/OD had failed to be proactive in their handling of vaccine safety issues, and you requested that Dr. Gerberding reply to your letter from a congressional representative before you made your presentation to the IOM." (See scanned Memorandum dated January 9, 2004.). I stand by that statement and I do not think it was unacceptable to convey that to Dr. Gerberding.

Elsewhere, there is a handwritten note from 2/4/2004:


Frank DeStefano called me in the evening and told me that Bob Chen wanted to fire me. I asked why Bob would be able to fire me? Frank didn't give any clear reason why. He suggested my e-mails provided clear reasons to fire me.

Penina Haber subsequently told me that Frank had asked her to call first and she declined.

And another annotation (click to embiggen) from 2/12/2004:


Things to Do 2/12/2004
① Bill Martin 9:00 AM
② Frank DeStefano 12:00 Lunch
— at lunch I told Frank I was pleased that he told me I was going to be fired.
③ Jan Burton 1:30 - 4:30
④ Cash for Mrs. B. $180
⑤ Hospitalization Manuscript

Why would Bob Chen have wanted to fire Thompson? It's not entirely clear from the documents, but Thompson was clearly making trouble—and not just about the Atlanta MMR-autism study. It's also not clear why it was Frank DeStefano who ended up warning Thompson his job was in danger. What were the reasons Thompson's job was in jeopardy? This letter telling Thompson he was being put on administrative leave lists several instances of inappropriate and unacceptable behavior and makes it sound as though this action was being taken out of concern that Thompson was under extreme stress, which was certainly possible, given what we know from Hooker and Wakefield's complaint to the CDC and Thompson's own words in the transcripts of his phone conversations with Hooker. The letter notes the issue described above by Thompson as well as:

- Refusing to assist Dr. Gina Mootrey when she asked Thompson to clarify some points in a slide presentation regarding influenza so that Dr. Walter Orenstein could modify some of the slides for a different presentation.
- Approaching Dr. Orenstein in the parking lot and demonstrating "inappropriate anger towards Dr. Orenstein, his request, and your perception that Dr. Orenstein was responsible for permitting a hostile environment within your organizational unit.
- Sending emails to Dr. Orenstein requesting an apology
- Writing emails to senior staff complaining about Dr. Orenstein, accusing him of harassment.

The final paragraph:

The general tone and content of your e-mails were inappropriate and gave the appearance that senior management had not fulfilled their public health obligations as they pertain to vaccine safety. Your actions had the effect of eroding the employment relationship between supervisor and subordinate, and appear to make a mockery of management's authority to direct the activities of this office. Furthermore, your interaction with Dr. Orenstein created concern about your level of anger being out of proportion to the facts.

One notes that none of these incidents, with the possible exception of Thompson's e-mails complaining about the leadership's handling of vaccine safety issues, appears to have had anything to do with the DeStefano et al study. Interestingly, the memo specifically said that it would not be placed in Thompson's Official Personnel Folder, which means Thompson himself must have included it in the document dump to Rep. Posey's office. This implies that Thompson likely wanted it to be seen by Posey, perhaps as "evidence" of "persecution" or retaliation for his complaints about the study that became DeStefano et al. Moreover, given that we know from elsewhere in the documents and from transcripts of his discussions with Brian Hooker that Thompson really, really wanted a congressional hearing on what he viewed as a coverup, he

must have been OK with these documents becoming public. After all, that's what would have happened if he had gotten what he wanted. In any event, it's clear that Thompson appears to have had (and probably still has) what are referred to as anger issues. This is consistent with previous evidence that we have suggesting that Thompson doesn't play well with others.

So what emerges from all these documents? One thing that doesn't emerge is any evidence of a coverup. There's no contemporaneous documentation to suggest an effort to "hide" findings viewed as "inconvenient," although Thompson's retroactive markups of the meeting agendas sure tries to make it seem as though there were. In the end, after this document dump, we're left with no evidence of scientific malfeasance or attempts to whitewash data. Even in the part where Thompson states that the co-investigators got together to throw unneeded documents in the wastebasket, one has to wonder: What was thrown away? If this document dump is any indication, they probably got rid of old meeting agendas and old drafts of the protocol. No wonder Matt quipped, "I hope people at CDC are not keeping all this paper." Even Thompson notes that all the original computer files still reside on CDC servers.

All of this brings us back to a point that Matt makes regarding whether it was a good idea to leave out the spurious statistically significant result:

Ah, one will say, what about the finding of an association between the MMR and autism for African American boys vaccinated late (between 18 months and 36 months)? Why wasn't that included in the published paper or public presentations? The reasons given by Thompson/Hooker/Wakefield don't hold water as I've shown. So, what was the scientific reason for not including this result in the paper? Many online writers have discussed how weak this result is; how it is a spurious result. But I'd like to know the reasoning at the time behind the CDC decision to leave this out. As a community member–an autism parent–I'd like to see all the results and understand the reasons why certain results are spurious. Of course it is easy to say now, but leaving this out of the public's eye was a mistake. It gave Thompson, Hooker and Wakefield the chance to cherry pick, hide information and craft a story that has been very damaging to the autism communities and to public health.

Matt has a point. On the other hand, as a scientist myself, I realize that decisions are made all the time over what data to include and exclude from a manuscript. We frequently leave out raw data that seemed statistically significant at first but didn't hold up to correcting for confounders. But, then, I don't do research in an area where antiscience loons are waiting to pounce on any inconsistency in order to sow fear and doubt, something we know antivaccinationists were doing even in 2004 when the manuscript that became DeStefano et al was being written and submitted for publication. Still, it must be noted that word limits and limits on the number of figures and tables were generally tighter in 2004; it's not like today, when journals seemingly encourage authors to dump every last bit of data that isn't in the paper itself into supplementary online files, a practice that I've found to be a mixed blessing. It was necessary back then to be a lot more selective about what went into a paper because you couldn't just dump everything else into supplemental figures.

Even so, although it's easy to ask why the CDC didn't see the potential for mischief at the time, it's important to note that we're viewing history through the retrospectoscope, which, as everyone knows, is 100% accurate. At the time, how could anyone ever have predicted that Thompson's disillusionment and anger at his colleagues would lead him to pal around with Brian Hooker and funnel enough information to Hooker and Wakefield to make so much mischief? Maybe if the leadership had seen the handwritten note included in this document dump) that Thompson made to himself to get Andrew Wakefield's contact information, there might of some

indication. (Yes, it's true, Thompson appears to have been in contact with Wakefield—or at least tried to contact him—12 years ago; see pp 66-68 in document A000561. Outside of that it's hard to think of something that would have allowed the CDC leadership to have predicted this. That's not to say that the CDC leadership is without blame; based on the contents of these documents, it's hard not to conclude that it could have done a better job of dealing with a troubled employee.

One thing's for sure. As unrevealing as Thompson's document dump is, you can be sure that the antivaccine movement will, reality be damned, continue to spin it as proof of a coverup. Same as it ever was.

Miranda (Randy) Katsoyannis
CDC Washington Office
202-245-0600
www.cdc.gov/washington

From: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Sent: Thu, 28 Apr 2016 17:17:21 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Harben, Kathy (CDC/OD/OADC); Reynolds, Barbara S. (CDC/OD/OADC)
Subject: Fw: Google Alert - CDC-

Fyi-the article below mentions a press release that went out today.
Sent from my BlackBerry 10 smartphone on the Verizon Wireless 4G LTE network.

From: (b)(6)
Sent: Thursday, April 28, 2016 5:11 PM
To: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Subject: Fwd: Google Alert - CDC whistleblower

Sent from my iPhone

Begin forwarded message:

From: Google Alerts <googlealerts-noreply@google.com>
Date: April 28, 2016 at 10:06:00 AM EDT
To: (b)(6)
Subject: Google Alert - CDC whistleblower

Google Alerts

CDC whistleblower

Daily update - April 28, 2016

BLOGS

CDC Whistleblower Scientist Given Huge Bonus and Asked to Rewrite Fraudulent Vaccine-Autism ...
Health Impact News
Health Impact News Editor Comments. Brian Hooker, Ph.D., issued a press release today clarifying some issues related to his past relationship to Dr.

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Send Feedback

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Fri, 10 Oct 2014 17:52:15 +0000
To: Ikeda, Robin (CDC/ONDIEH/OD); Jaffe, Harold W. (CDC/OD/OADS)
Cc: Bonzo, Sandra E. (CDC/ONDIEH/OD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: FW: Kemper: Follow-up Regarding the 2004 Autism Paper

Robin and Harold: Please see the attached request from the Editors on Pediatrics for access to the public use data file for the MMR-Autism study. Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Friday, October 10, 2014 12:41 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: FW: Kemper: Follow-up Regarding the 2004 Autism Paper

Good afternoon Coleen,

I hope you are well. I noticed Betsy is out of the office. Dr. Kemper from *Pediatrics* is looking for an alternative way to access the MMR and autism data. He finds the current way too lengthy, his message is below. He states that their interest in acquiring the dataset is "for the sole purpose of replicating the analysis as described in the final analysis plan."

Is there an alternative way? Let me know if you like me to call you to discuss.

Regards,
Belsie

Belsie González, MPH
Senior Public Affairs Specialist

News Media Branch | Division of Public Affairs
Office of the Associate Director for Communication
Centers for Disease Control and Prevention (CDC)
bgonzalez2@cdc.gov | 404-639-0668

From: Alex Kemper, M.D. [mailto:(b)(6)@duke.edu]
Sent: Friday, October 10, 2014 12:30 PM
To: Gonzalez, Belsie (CDC/OD/OADC)
Cc: Lewis First
Subject: Re: Follow-up Regarding the 2004 Autism Paper

Belsie,

I reviewed the material on the webpage – it looks like there is a fairly extensive process to get access to the dataset, include external peer review of an 8-page or so request, documentation of expertise, and a letter from the home institution. We are interested in acquiring the dataset for the sole purpose of replicating the analysis as described in the final analysis plan.

It also sounds like the review process can be lengthy and there is no guarantee of access to the data.

I can certainly understand this policy as a general rule. However, we want to replicate the analysis solely to satisfy ourselves (and in turn our readers) that the report, as published in 2004, is accurate. We do not want to explore any hypothesis not specifically outlined in the protocol you sent nor do we want to engage in any new analysis. I wonder if there is an alternative way for us to access these data.

Please let me know if you would prefer to talk.

Alex

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 19 May 2016 19:27:26 +0000
To: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Subject: FW: Mercury Vaccine Connection

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Colleen Hamson [mailto:(b)(6) @yahoo.com]
Sent: Thursday, May 19, 2016 2:55 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: Mercury Vaccine Connection

Dear Coleen,

Your Bernie Sanders post was deleted this morning because one mother from Oregon shared clinical studies that raised a fuss. Clinical studies and reviews are publicized and available for all. How can something be untrue when based in fact?

(b)(6)

Therefore, I have studied for 12 years.

So many of our government officials have ties to Monsanto, the manufacturer of glyphosate-based herbicides. I know my children would not be sick if it weren't for these and other preventable toxins. Does Monsanto have all of you by the throat?

MERCURY - HERBICIDE - VACCINE CONNECTION

Mercury based preservatives are still being used in packaging of vaccines in trace amounts.
In these trace amounts metal toxicity such as mercury has been found to be enhanced by GLYPHOSATE-BASED HERBICIDES used in GMO practices in American crops. These herbicides are found to REDUCE THE BODY'S ABILITY TO ELIMINATE TOXIC METALS.

I have learned that the MERCURY BASED PRESERVATIVE Thimerosal HAS BEEN ALLOWED BY THE FDA TO BE USED IN VACCINE PACKAGING (in trace amounts) WHILE STILL BEING LABELED "MERCURY-FREE"

Here are the studies.

FIFTH PARAGRAPH DOWN
http://www.fda.gov/BiologicsBloodVaccines/Vaccines/QuestionsaboutVaccines/UCM070430

http://www.gmoseralini.org/wp-content/uploads/2013/01/Gasnieral.TOX_2009.pdf

HERE IS THE AUTISM - MERCURY CONNECTION SOURCE: http://www.omicsonline.org/open-access/the-possible-association-between-elevated-levels-of-blood-mercury-and-the-increased-frequency-of-serum-antimyelin-basic-protein-autoantibodies-in-autistic-children-2155-9899-1000310.php?aid=51825

I apologize for the caps. I wasn't yelling, I was merely trying to make it look a bit like a meme.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 6 Nov 2014 19:30:52 +0000
To: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Subject: FW: MMR and autism

FYI

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
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cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, November 06, 2014 1:47 PM
To: Gonzalez, Belsie (CDC/OD/OADC)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: MMR and autism

Hi Belsie,
This is a message from a UK colleague. This is the first I've heard about a possible BMJ article and don't know anything more about it. We may have to be prepared to respond, but most of the communication staff here is tied up with Ebola.
Frank

From: Liz Miller [mailto:(b)(6)
Sent: Thursday, November 06, 2014 1:28 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: MMR and autism

Dear Frank

You may remember me from the MMR and autism days. The issue has resurfaced again in the UK as Brian Deer a journalist who exposed Wakefield's inappropriate conduct with respect to his Lancet study has now written an article for BMJ about the CDC study and the recent issues about the subgroup analysis in Afro Americans. He has spoken to Brian Hooker so not sure what line Deer will take. We have taken the line that the article by Hooker has been withdrawn and that CDC stands by its original analysis which we will reiterate but wondered whether you have any plans afoot to do any re-analyses or take the issue further. Is it the case that there will be a congressional review again on this?

Anyway we need to be prepared should this issue resurface and generate media interest again in the UK so any background you can give us would be helpful.

With best wishes

Liz

Professor Elizabeth Miller
Immunisation Hepatitis and Blood Safety Department
Public Health England
61, Colindale Avenue NW9 5EQ
London, UK
Direct line (b)(6)
Mobile (b)(6)

From: Peacock, Georgina (CDC/ONDIEH/NCBDDD)
Sent: Fri, 5 Sep 2014 15:48:18 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: FW: MMR Vaccine and African American Boys – Talking Points
Attachments: MMR Autism study2.docx

I wanted to share this with you from the AAP Council on Children with Disabilities and Autism Subcommittee.
Let me know if you need me to get any more information or connect with Stephanie Mucha.
Thanks
Georgina

From: Autism Subcommittee [mailto:ASC@LISTSERV.AAP.ORG] **On Behalf Of** Mucha, Stephanie
Sent: Friday, September 05, 2014 3:23 PM
To: ASC@LISTSERV.AAP.ORG
Subject: MMR Vaccine and African American Boys – Talking Points

COCWD EC and ASC Members,

We have been closely monitoring the recent information and coverage of the *Pediatrics* article, "Age at First Measles-Mumps-Rubella Vaccinating in Children with Autism and School-matched Control Subjects: A Population-Based Study in Metropolitan Atlanta," as well as a recent Brian Hooker article, "Increased Incidence of Autism in African-American Boys." We have also been in touch with our colleagues at the CDC.

A decision was made to develop some informational talking points, with input from Dr Hyman, should parents have concerns or questions—they are attached. We are only sharing this document with select spokespersons, our autism experts, and pediatricians who request help with this issue. If demand grows, we can change course and post it online for AAP members.

Have a good weekend,
Stephanie

Stephanie Mucha, MPH
Children with Special Needs Initiatives
Disabilities – Autism – Transitions – Care Coordination
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MMR Vaccine and African American Boys

Sept. 5, 2014

Below is background and key points that may be helpful for AAP members in responding to parents' questions regarding the 2004 Pediatrics article, "Age at First Measles-Mumps-Rubella Vaccinating in Children with Autism and School-matched Control Subjects: A Population-Based Study in Metropolitan Atlanta," as well as a recent Brian Hooker article, "Increased Incidence of Autism in African-American Boys." Shortly after publication, Translational Neurodegeneration announced it was removing Brian Hooker's article from the public domain "because of serious concerns about the validity of its conclusions."

Background

In February 2004, Pediatrics published a case-control study by DeStefano, et al. that compared ages at first measles-mumps-rubella (MMR) vaccination between 624 children with autism and 1,824 developmentally healthy children. Researchers found most children in both groups were vaccinated between 12 and 17 months of age. They found no link between the age children were given their first MMR vaccine and autism diagnoses. Nor did they find a statistically significant increase for a particular racial group.

Brian Hooker, an associate professor of biology at Simpson University in Redding, Calif., studied the same data set and published a reanalysis in August 2014. He concluded the data show an increased risk of autism in African American boys who received their MMR vaccine before the age of 3. The publication was accompanied by a news release and a video narrated by Andrew Wakefield that claimed a CDC whistleblower, one of the researchers on the 2004 paper, alleged the original data were skewed by a decision to exclude children for whom birth certificates were not available.

CDC issued a statement explaining the reason for limiting the data set to children with birth certificates. According to the CDC, information on the birth certificates allowed researchers to assess other important characteristics, including possible risk factors for autism such as the child's birth weight, mother's age, and education. The authors suggest higher autism rates among children vaccinated before age 3 was likely due to school entry vaccine requirements for special education programs. Unvaccinated children identified as being delayed could not enter school programs. CDC stands by the 2004 paper and has stated that there was no cover-up.

William Thompson, a CDC researcher involved in the original 2004 Pediatrics paper, issued a statement explaining he had been secretly taped by Brian Hooker. While he had concerns about how the original data were examined, he expressed his belief that parents should continue to vaccinate.

Talking points

Brian Hooker's re-analysis of the CDC data has serious flaws that influence the interpretation. The 2004 study was set up as a case-control study. This means children with autism (cases) were specifically identified, and children without autism (controls) were identified to be similar to the children with autism in other respects. When data are collected for a specific type of statistical analysis, using those data in a different type of analysis can produce confusing results. Dr. Hooker's reanalysis uses a different study design. Because the methods in Dr. Hooker's reanalysis were not described in detail, it is hard to speculate why his results differed from CDC's.

Other independent researchers have pointed out flaws in Dr. Hooker's methodology and the journal has removed it from publication pending an investigation.

The conclusion reached by Dr. Hooker's paper does not align with other research documenting the age of autism diagnosis in children of various racial groups and genders.

Pediatrics investigated the allegations regarding the 2004 article in accordance with the Committee on Publication Ethics guidelines and has decided that a retraction is not warranted.

Multiple peer-reviewed studies published since 2004 have confirmed that MMR vaccine does not increase the risk of autism. When multiple studies confirm a finding, we are more confident in the conclusions. This is the way science works. The 2004 Pediatrics study does not stand alone … it has been confirmed by other researchers.

In 2004, the Institute of Medicine reviewed published and unpublished findings from the U.S. and other countries and concluded that there was no association between MMR vaccination and autism. In 2011, another IOM committee reviewed additional research, and again concluded the evidence showed no association.

No single cause of autism has been identified, but science has shown there is a clear genetic component. For example, siblings of children with ASD have a higher likelihood of being diagnosed with an ASD. Researchers also are exploring what environmental factors during pregnancy could affect the developing brain.

One exposure that has been studied extensively is vaccines. The AAP wants to reassure parents that current scientific studies show no link between vaccines and autism. Many studies have looked at this, and none has found a link to date.

Families should discuss concerns they have about vaccines and any aspect of health promotion with their primary care provider.

According to the 2013 National Immunization Survey, the vast majority of parents in the U.S. are making sure their children are vaccinated against serious diseases. Nationally, vaccination coverage among children ages 19-35 months old increased or remained stable in 2013 for all routinely recommended childhood vaccines.

However, pockets of unimmunized and under-immunized children create vulnerable areas to disease. This year has seen the highest number of measles cases in the U.S. since 1994. Measles can spread quickly among unvaccinated populations. Vaccine preventable illness is real and increasing. The AAP is committed to promoting the health of ALL children.

For additional resources on autism, visit www.aap.org/autism
For additional resources on immunizations, visit http://www2.aap.org/immunization/

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Wed, 22 Oct 2014 10:50:44 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Fw: MMR/autism Data

FYI.

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, October 22, 2014 10:46 AM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Fw: MMR/autism Data

Dear Joanne,

Please see message from Andy Autry. We have made copies of both datasets. Andy is also available to answer any questions you or any members of the committee might have.

Please let me know how you would like to proceed.

Thank you.
Marshalyn

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, October 22, 2014 10:33 AM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: MMR/autism Data

Hi Marshalyn –

I just wanted to confirm what we talked about today. There are two MMR/autism data files: the public use file and the analysis file.

- The analysis file contains all of the variables, including potentially identifiable information (at least one of the 18 data elements enumerated in the HIPAA law, usually dates and some levels of geography). The analysis file also contains the birth certificate variables which we get from the state. That is what they used to generate the tables in the MMR/autism paper. The analysis file is a sas data set. The only data documentation that I could find in Tanyas files is the comments on the variables themselves. You will also need the analytic code to create the actual analysis variables (in the first part of the code) and then run the analysis (second part of the code) on the analysis variables created.
- The public use file contains the data in the analysis file with the following exceptions:
    - All of the 18 HIPAA identifiers were removed, including all dates and geography; the dates of things like vaccinations were changed to ages at the event. Any geographic identifiers, like schools and school systems served and counties resided in were removed.
    - All birth certificate variables were removed (because the state did not give us permission to share).

The public use file is a fixed width ASCII file and has Data Documentation to go along with it. You must have the data documentation in order to restore the file to what ever stat software youre using and then run the analysis. The data documentation is extensive.

Please let me know if I can provide any additional information. Thanks!

Andrew R. Autry, PhD
IT Project Manager
CDC/NCBDDD
1600 Clifton Road
MS E-86
Atlanta GA 30333
404-498-3876 (office)
(b)(6) ***(cell)***
I telework Wednesdays and Fridays.

(b)(5)

(b)(5)

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Mon, 16 Mar 2015 10:32:45 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper
Attachments: VAX PAPER master final march7.docx

FYI—not sure where this is coming out but JAMA possibly.

Cindy

From: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Sent: Monday, March 16, 2015 10:01 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Cc: Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper

FYI…I will let Betsy know as well.

From: Chan, C. Leah (CDC/ONDIEH/NCBDDD)
Sent: Friday, March 13, 2015 6:55 PM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD)
Cc: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper

FYI—there's an NIMH-funded paper coming out soon about the MMR vaccine and autism. Please see attached.

From: Pryzby, Rachel (CDC/OID/NCEZID) (CTR)
Sent: Friday, March 13, 2015 5:55 PM
To: Chan, C. Leah (CDC/ONDIEH/NCBDDD)
Subject: NIMH MMR vaccine and autism paper

Hey Leah,

I wanted to give you a heads up that there's an NIMH-funded paper coming out soon about MMR vaccine and autism. The findings are unsurprising (vaccines *still* do not cause autism!), but HHS thinks it might get some media attention because of the measles outbreak.

Since this is NIMH's paper, we won't need to develop talking points or anything like that. But I am going to coordinate with NIMH to make sure our messaging is in sync. I will loop you in once I hear from them.

Thanks! Have a great weekend.

Rachel

Rachel Pryzby, MPH, CHES
Health Communications Specialist
Chenega Government Consulting
Immunization Safety Office, Division of Healthcare Quality Promotion
Centers for Disease Control and Prevention
404-639-1828
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Note: I telework Wednesdays, Fridays, and every other Monday. I can be reached by email or cell (b)(6)

Title page:

Autism occurrence by MMR vaccine status among US children with older siblings with and without autism

Authors: Anjali Jain, MD, Jaclyn Marshall, MS, Ami Buikema, MPH, Tim Bancroft, PhD, Jonathan P. Kelly, MPP, Craig J. Newschaffer, PhD

Affiliations: Dr. Jain, Ms. Marshall, and Mr. Kelly are affiliated with The Lewin Group, Falls Church, VA. Ms. Buikema and Dr. Bancroft are affiliated with Optum, Eden Prairie, MN. Dr. Newschaffer is affiliated with the A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA.

Word Count: 3500

Address Correspondence to: Anjali Jain, The Lewin Group, 3130 Fairview Park Drive, Suite 500, Falls Church, VA, 22042, anjali.jain@lewin.com, 703-269-5537.

Date of revision: March 7, 2015

Abstract

Importance: Despite research showing no link between measles-mumps-rubella (MMR) vaccine and autism spectrum disorders (ASD), beliefs that the vaccine causes autism persist, leading to lower vaccination levels. Parents who already have a child with ASD may be especially wary of vaccinations.

Objective: To report ASD occurrence by MMR vaccine status in a large sample of US children who have older siblings with and without ASD.

Design, setting, participants: A retrospective observational cohort study using an administrative claims database associated with a large commercial health plan, 1997-2012. Participants included children continuously enrolled in the health plan from birth to at least 5 years of age during 2001-2012 who also had an older sibling continuously enrolled for at least 6 months between 1997 and 2012.

Exposures: MMR vaccine receipt (0, 1, 2 doses) between birth and 5 years of age.

Main outcome measure: ASD status defined as two claims with a diagnosis code in any position for Autistic Disorder, other specified Pervasive Developmental Disorder (PDD), including Asperger's disorder, or unspecified PDD (ICD-9-CM 299.0x, 299.8x, 299.9x).

Results: Of 95,727 children with older siblings, 1,929 (2%) had an older sibling with ASD. Among children who had an older sibling with ASD, MMR vaccine receipt was not associated with an increased risk of ASD at any age. At age 2, the adjusted relative risk (RR) =0.76 (95% CI 0.49, 1.18; p=0.22), and at age 5, the RR=0.56 (95% CI 0.31, 1.01; p=0.05). Among children whose older siblings did not have ASD, MMR vaccine was also not associated with an increased risk of ASD at any age. At age 2, the RR=0.91 (95% CI 0.67, 1.20; p=0.50) and at age 5, the RR=0.74 (95% CI 0.55, 0.99; p=0.05).

Conclusions and Relevance: In this large sample of privately insured children with older siblings, receipt of MMR vaccine was not associated with increased risk of ASD regardless of whether older siblings had or did not have ASD. These findings indicate no association between MMR vaccine receipt and ASD even among children already at higher risk for ASD by virtue of having an older sibling with ASD.

Introduction

Two doses of measles-mumps-rubella (MMR) vaccine are currently recommended for children in the US: the first at 12-15 months of age and the second at 4-6 years.[1] While a substantial body of research over the last 15 years has found no link between the MMR vaccine and autism spectrum disorders (ASD),[2,3,4] parents and others continue to associate the vaccine with ASD.[5] Parents cite vaccinations, especially MMR, as a cause of ASD,[6] and have deferred or refused vaccinations for their children as a result.[7,8] Lower vaccination levels threaten public health by reducing both individual and herd immunity and have been associated with several recent outbreaks of measles, with most cases occurring among the unvaccinated.[9]

Families with a child affected by ASD may be particularly concerned about reports linking MMR and ASD, despite the lack of evidence.[10] Surveys of parents who have children with ASD suggest that many believe vaccination was a contributing cause.[11] This belief, combined with knowing that younger siblings of children with ASD are already at higher genetic risk for ASD compared to the general population,[12,13,14] might prompt these parents to avoid vaccinating their younger children. In a recent survey of 486 parents of children with ASD nearly 20% had declined or delayed MMR immunization in the younger siblings of children with ASD.[15] Furthermore, a Canadian study of 98 younger siblings of children with ASD found that younger siblings were less likely to be fully MMR-immunized compared to their older siblings with ASD. However, there were no statistically significant differences in rates of ASD diagnosis between immunized and non-immunized children.[10] To our knowledge, this very small study is alone in examining MMR immunization and ASD outcomes among the younger siblings of children with ASD.

Thus, we set out to report on ASD occurrence by MMR vaccine status in a large sample of US children having older siblings with ASD and to compare findings to those among children who have older siblings without ASD.

Methods

A retrospective cohort study was conducted using an administrative claims database associated with a large, US health plan (the Optum Research Database, or ORD). The ORD includes more than 34 million individuals each year, containing both commercially-insured individuals and Medicare Managed Care enrollees. The database consists of proprietary, de-identified health claims data from a geographically diverse US population (16% West, 20% Midwest, 36% South, and 27% Northeast). In addition, the age and gender distribution of the enrollees is similar to that reported by the US Census Bureau for the commercially insured and the Medicare Managed Care population. The New England Institutional Review Board waived the need for informed consent and deemed the study exempt under category E for the study of existing, de-identified[16] data in November 2013.

Index children were identified among commercially-insured enrollees who had both medical and pharmacy coverage and included all children in the database born between 01 January 2001 and 31 December 2007 who were continuously enrolled in the health plan from birth to at least 5 years of age and who also had an older sibling continuously enrolled in the health plan for at least 6 months between the beginning and end of the study period, 1 January 1997 through 31 December 2012. Older siblings of index children were identified using a family identifier variable associated with the insurance policy; siblings had to be between 0.5-17 years older than the index child to be included.

ASD status in index children and older siblings was determined using a claims-based algorithm[17] that required two or more claims on separate dates of service with an ICD-9 diagnosis code in any

position for: Autistic Disorder, other specified Pervasive Developmental Disorder (PDD), including Asperger's disorder, or unspecified PDD (299.0x, 299.8x, and 299.9x). Both index child and older sibling ASD status were determined using their entire enrollment time that fell within the study period. Index children had to have at least one older sibling with two claims with ASD diagnoses, or all older siblings with no ASD diagnoses. Children with an older sibling with only one diagnosis of ASD were excluded. Index children with only one diagnosis of ASD were also excluded.

MMR vaccine receipt was defined as having a Current Procedural Terminology (CPT) or International Classification of Diseases, Ninth Revision (ICD-9) procedure code indicating receipt of each component (M, M, and R) between birth and five years of age (see eTable 2). The date of administration of the trivalent MMR (or the last-administered component of monovalent vaccines) was used to determine age at administration for each dose (first or second).

Because the recommended age of first MMR dose administration is 12 to 15 months, and 4 to 6 years for the second dose, relative risks (RRs) were estimated to compare ASD status in children receiving one-dose of MMR at ages 2, 3, 4 and 5, and two-doses at age 5 to those who were unvaccinated at those ages (two dose RRs at age 4 would only include those children who received the second dose by their 4^{th} birthday). Separate RRs were estimated for children with older siblings with and without ASD. Since no subjects were lost to follow-up before age 5, unadjusted RRs were reported as cumulative incidence rate ratios, calculated simply by taking the ratio of the proportion of subjects who had an ASD diagnosis in an exposed group (either one MMR dose or two MMR doses) to the proportion of subjects who had an ASD diagnosis in the unvaccinated group at a given age.

Adjusted RRs were reported as hazard rate ratios estimated from a single Cox proportional hazard regression model that used age since birth as the time-scale and included MMR receipt as a time-varying covariate ascribing follow-up time to either the unvaccinated group, the one-dose

group, or the two-dose group depending on immunization status at any given age. An interaction term between MMR receipt and older sibling ASD status was included to all adjusted RRs to vary by older sibling ASD status. In addition, interactions between MMR receipt and age (to relax the proportionality assumption and allow hazard ratios (HRs) to vary by age) as well as a three-way interaction between MMR receipt, age, and older sibling ASD status were tested for possible inclusion in the final model.

Both time-varying and fixed covariates were also included in adjusted models to control for potential confounding. Separate claims-based indicators of the presence of seizures and vaccine-related allergies in the index child were included as time-varying covariates because they are possible contraindications to vaccines and are, or are potentially, associated with ASD status.[18,19,20] To capture aspects of the index child's overall health status that might also be associated with both MMR receipt and ASD status, an indicator for preterm birth and a modified, claims-based version[21] of the childhood chronic conditions score (CCC)[22] were included as fixed covariates. The modified CCC uses claims-based diagnosis codes to capture the presence of chronic conditions, excluding those associated with ASD, within nine domains: 1) neuromuscular, 2) cardiovascular, 3) respiratory, 4) renal, 5) gastrointestinal, 6) hematologic or immunologic, 7) metabolic, 8) other congenital or genetic defects, and 9) malignant neoplasms. The presence of at least one claim for a condition within each domain between birth and age 2 adds one point to the CCC score, which ranges from 0 to 9. See eTable 3 for ICD-9 codes used to define conditions and variables.

Maternal/paternal educational level, household income, and race/ ethnicity were also included as fixed covariates. These sociodemographic factors have been associated with both ASD status[23] and vaccine receipt.[24] Approximately 30% of the race/ethnicity data in this study were collected directly from public records (e.g. driver's license records), while the remaining data were imputed using commercial software (E-Tech by Ethnic Technologies LLC. South Hackensack, NJ) that

uses algorithms developed with Census data ZIP codes (ZIP+4) and first and last names. This imputation method has been validated and demonstrates 97% sensitivity, 48% specificity and 71% positive predictive value for estimating the race of Black individuals.[25] Individuals categorized as "other/unknown" for race/ethnicity were those whose race/ethnicity could not be assigned by the imputation algorithm or who were added to the dataset after the imputation had been performed.

Other fixed covariates included in the adjusted models were index child gender, mother's and father's age at index child's birth, geographic location defined by the four US Census regions, mental health benefits, and index child birth year which was included to adjust for varying opportunity to develop/diagnose ASD. Response categories were created for unknown or missing values of all covariates and included as such in regression models.

A series of sensitivity analyses were conducted to explore the influence of potential MMR or ASD status measurement error on results. Quantitative bias analyses were implemented for both exposure and outcome misclassification following the approach described in Lash et al (2009.[26] More detail on bias analysis methods are provided in the online-only supplement (See "Sensitivity Analyses for Exposure and Outcome Misclassification" and eTable 1). In addition, associations between MMR receipt and ASD risk were also re-estimated using a less-restrictive one-claim criterion for ASD diagnosis in younger siblings. Finally, an additional sensitivity analysis was also performed rerunning final models on the subset of subjects with no missing data on any covariates.

Two-sided statistical significance testing of unadjusted rate ratios was conducted using Yates chi-squared test and two-sided statistical significance testing of hazard ratios estimated by maximum likelihood were conducted using Wald chi-squared statistics. Likelihood ratio tests were used to

test the significance of Cox proportional hazards models with and without interaction terms. The alpha level for all tests was 0.05. Analyses were performed in SAS 9.2 (SAS Institute, Cary NC).

Results

Out of 95,727 children in the cohort, 1,929 (2%) had an older sibling with ASD. Overall, 994 (1%) children in the cohort had ASD diagnosed during follow-up. Among those who had an older sibling with ASD, 134 (6.9%) were diagnosed with ASD, compared to 860 (0.9%) diagnosed with ASD among those with siblings without ASD (6.9% vs. 0.9%, $p<0.001$). The MMR vaccination rate (at least one dose) for the children with unaffected siblings (siblings without ASD) was 84% at 2 years and 92% at age 5. In contrast, the MMR vaccination rates for children with older siblings with ASD were markedly lower - 73% at age 2 and 86% at age 5.

Table 1 shows the clinical and socio-demographic characteristics of the 95,727 children stratified by older sibling ASD status. Birth years were roughly equally distributed over 2001-2007, and a little more than half the sample was male. About three quarters were white; blacks were underrepresented at ~3% (compared to 13% in the U.S. population) and Hispanics made up ~9% (compared to 17% in the U.S. population).[27] All four of the major geographic regions in the US were represented, with somewhat more representation in the south (42% vs. 38%) and less in the west (17% vs. 24%) as compared to the overall U.S. population.[27] About 3% had a potential contraindication to vaccine receipt and about 8% were preterm. The average length of continuous enrollment was just over 7 years.

Table 2 includes unadjusted relative risks of ASD (cumulative incidence rate ratios) associated with receiving either one MMR dose or two MMR doses (compared to no doses) at ages 2, 3, 4 and 5 years separately in children with and without older siblings who have ASD. The unadjusted RR for one dose of MMR at age 2 years among children with unaffected older siblings was 0.80 (95% CI 0.44, 1.47; p=0.58) and 0.44 (95% CI 0.15, 1.29; p=0.22) among children with older

siblings with ASD. Similarly, at ages 3, 4 and 5, no association was found between one dose of MMR and ASD among index children, irrespective of whether their older siblings had ASD. For two doses of MMR at age 5 years, the unadjusted RR was 0.74 (95% CI 0.55, 0.99; p=0.05) among children with unaffected older siblings and 0.44 (95% CI 0.26, 0.75; p<0.01) among children with older siblings with ASD.

Table 2 also shows adjusted RRs (hazard rate ratios) estimated from the Cox proportional hazards model. Interactions between MMR receipt and older sibling ASD status as well as MMR receipt and younger sibling age both significantly improved the fit of a base main effects only model (p=0.048, and p=0.015, respectively) and were thus retained in the final model. The addition of the three-way interaction between MMR receipt, age, and older sibling ASD status provided no additional improvement in model fit (p=0.382) and was not retained.

In general, adjusted one-dose RR estimates were closer to the null than unadjusted estimates and none of the one-dose RR estimates at any age were statistically significant. The adjusted RRs for one dose of MMR at age 2 years was 0.91 (95% CI 0.67, 1.20; p=0.50) among children with unaffected older siblings and 0.76 (95% CI 0.49, 1.18; p=0.22) among children with older siblings with ASD. At five years the adjusted RRs for one dose of MMR were 1.10 (95% CI 0.76, 1.54; p=0.58) and 0.92 (95% CI 0.58,1.44; p=0.71), respectively. There appeared to be a similar influence of adjustment on the two-dose RR estimates, although the RR estimate in children with affected older siblings approached statistical significance. These adjusted RRs were 1.12 (95% CI 0.78, 1.59; p=0.55) and 0.56 (95% CI 0.31, 1.01; p=0.05) in children without and with affected older siblings respectively.

Quantitative bias analysis suggested that the influence of potential under-reporting of MMR immunization in our claims data on RR estimates would be modest and toward the null. Non-differential outcome misclassification, if present, would appear to have a very small additional

biasing effect toward the null. Differential outcome misclassification, if present, would most likely manifest as greater outcome detection sensitivity among those vaccinated then among those not vaccinated, would make actual RRs smaller than those reported. These bias analyses are informative, but need to be cautiously interpreted given the assumptions involved. More detail is provided in the online-only supplement.

In other sensitivity analyses, we saw that results were not substantively different in Cox models that used the presence of just one claim with ASD to define outcome (see eTable 4). In addition, the original Cox model was rerun excluding the 19% of the sample that was missing some sociodemographic data, again, results were not substantially changed (see eTable 5).

Comment

Consistent with studies in other populations,[2,3,4] we observed no association between MMR vaccination and ASD risk among privately insured children. We also found no evidence that receipt of either one or two doses of MMR vaccination was associated with an increased risk of ASD among children who had older siblings with ASD, a group of children who are particularly important as they are often under-vaccinated in our observations as well as in previous reports.[10,15]

Although we did not see any statistically significant relative risk estimates indicating increased ASD risk at any age in either group of children—those whose older siblings had or did not have ASD—the statistically significant interactions in the final Cox model suggests differences in relative risk by both age and older sibling ASD status. The pattern in relative risks across these groups was such that lower RR estimates (commonly extending into the protective range, i.e.,below 1.0) were observed at younger vs. older ages and in children with older siblings with vs. without ASD. Although protective estimates tended not to reach statistical significance, this pattern is worth further consideration. It is possible, for example, that this pattern is driven by selective parental decision-making around MMR immunization where parents who notice social

or communication delays in their children decide to forestall vaccination. Because, as a group, children with recognized delays are likely to be at higher risk of ASD, such selectivity could result in a tendency for some higher risk children to be unexposed. To be consistent with observed data, this would need to happen more often at younger ages. This seems feasible because, by the time the child is older, developmental concerns are more likely to have been confirmed or ruled out and parents may then be less worried about a new exposure—such as a vaccination—influencing a child's developmental trajectory. Estimates at older ages would thus be less susceptible to bias related to selective parental decision-making, which also aligns with the pattern observed here. This explanation would also suggest that the estimate for the one-dose RR estimate at age 5 (1.10; 95% CI 0.76, 1.54) is least vulnerable to this bias because age 5 is several years removed from the time parents are typically deciding about the first MMR dose or weighing the importance of early developmental concerns.

We also saw this tendency toward lower RR estimates for children whose older siblings had ASD, compared to those with unaffected older siblings. As seen in our data and other studies,[10,15] MMR immunization is lower in children with older siblings with ASD. It is also plausible that parents of affected older siblings would be especially attentive to developmental delays in their younger children and decide to forestall immunization. Among the younger siblings of children with ASD who were vaccinated with MMR, 38% of older siblings had their first ASD claim prior to the younger sibling's vaccination whereas more than half of the younger siblings of children with ASD who were not vaccinated had older siblings with an ASD claim by the time the younger sibling was due to receive MMR (data not shown). In other words, if the older sibling's ASD was known when MMR was due, vaccination was less likely in the younger sibling. Of course, developmental abnormalities in affected older siblings may also have appeared and raised parental concerns prior to encounters generating ASD claims. Note also that the contrast in relative risks between children with and without older ASD- affected siblings is most dramatic for

two doses at age 5; the ratio of the adjusted estimates at this age being 2.0 (1.12 / 0.56) for two doses compared to 1.19 (1.12 / 0.56) for one dose. This could reflect more older siblings being confirmed as having ASD between the younger siblings' recommended ages of first and second dose administration, potentially leading parents to raise de novo concerns about the vaccine's safety at the time second dose decisions are being made.

This study used a large administrative claims dataset spanning a recent 11-year period to examine associations between MMR immunization status and ASD risk in the US. The administrative claims database allowed for the prospective estimation of associations free from potential recall bias. However, administrative claims data do present some important research limitations. Claims are generated for payment, so diagnoses and procedures that don't affect payment are likely under-reported, diagnosis for conditions that may eventually be ruled out can be over-reported, and procedures and services that individuals receive through other payers may not be captured. We conducted a series of quantitative bias analyses to assess the potential impact of this measurement error and do not believe these are strongly influencing our findings. There are also potential inaccuracies in the identification of siblings from claims because of assumptions made about family relationships among individuals on the same health plan. However these are unlikely to be systematically related to either immunization status or ASD diagnosis.

For children born after a hypothetical link between MMR and autism risk was introduced, parental suspicion of developmental delay could influence MMR immunization decision-making. While the extent of this phenomenon is unknown, its existence is one explanation for the pattern of some of the RRs observed here. However, at ages and doses where this phenomenon would be least likely to be operating, there is no evidence of an association between MMR and autism risk.

Finally, these data and results are based on privately insured children with an extensive period – 5 years – of continuous enrollment in a single health plan and may not be completely generalizable

to other groups. The prevalence of ASD among all index children in the study sample was 1%, comparable to the current estimate of ASD prevalence of 1.5% in the general US population.[28] In addition, the younger siblings of children with ASD had a 6.9% risk of ASD themselves, also consistent with published estimates ranging from 6.4 to 24.7%.[12,13,14] Our findings may not be as applicable to more ethnically and socioeconomically diverse populations who have less access to health care services. For example, in our population the average age of ASD recognition based on claims was 4 years, several months earlier than the average age of ASD diagnosis in the US of 4 years, 5 months.[28]

Conclusion

In this large sample of privately insured children with older siblings, receipt of MMR vaccine was not associated with increased risk of ASD regardless of whether older siblings had or did not have ASD. These findings indicate no association between MMR vaccine receipt and ASD even among children already at higher risk for ASD by virtue of having an older sibling with ASD.

Acknowledgements

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Author Contributions: Ms. Buikema and Mr. Bancroft had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Jain, Newschaffer, Marshall, Buikema
Acquisition, analysis, or interpretation of data: All authors
Drafting of the manuscript: Jain, Marshall, Newschaffer,
Critical revision of the manuscript for important intellectual content: All authors
Statistical analysis: Newschaffer, Jain, Buikema, Bancroft
Obtained funding: Jain, Marshall, Newschaffer
Administrative, technical, or material support: Marshall, Buikema, Bancroft, Kelly
Study supervision: Jain, Marshall, Buikema

Other Contributors: Lee Brekke, PhD, an employee of Optum, provided assistance with statistical modeling and interpretation. Dr. Brekke did not receive compensation for his contribution to this manuscript and gave written permission for his name to be included in the Acknowledgments section.

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Disclaimer: The authors are solely responsible for the design, conduct, data analyses as well as drafting and editing of the manuscript and its final content. The contents of this manuscript do not represent the views of the National Institute of Mental Health, or the Federal Government.

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Table 1: Characteristics of study sample stratified by older sibling ASD status

	Older sibling without ASD (N=93,798) N (%)	Older sibling with ASD (N=1,929) N (%)
Birth year		
2001	11,292 (12.0)	188 (9.7)
2002	11,541 (12.3)	213 (11.0)
2003	12,194 (13.0)	239 (12.4)
2004	12,587 (13.4)	253 (13.1)
2005	14,121 (15.1)	325 (16.8)
2006	15,316 (16.3)	349 (18.1)
2007	16,747 (17.9)	362 (18.8)
Gender		
Male	47,917 (51.1)	975 (50.5)
Female	45,881 (48.9)	954 (49.5)
Geographic region		
Northeast	10,281 (11.0)	279 (14.5)
Midwest	27,497 (29.3)	588 (30.5)
South	39,698 (42.3)	771 (40.0)
West	16,291 (17.4)	290 (15.0)
Other	31 (<0.1)	1 (<0.1)
Race/Ethnicity		
White	68,524 (73.1)	1,509 (78.2)
African-American/Black	3,538 (3.8)	39 (2.0)
Native Hawaiian or Pacific Islander	81 (0.1)	0 (0.0)
American Indian or Alaskan Native	188 (0.2)	3 (0.2)
Asian	3,256 (3.5)	58 (3.0)
Hispanic	8,605 (9.2)	129 (6.7)
Other	1,614 (1.7)	28 (1.5)
Unknown/No SES	7,992 (8.5)	163 (8.4)
Household income		
Under $50,000	13,025 (13.9)	228 (11.8)
$50,000 - $74,999	21,413 (22.8)	411 (21.3)
$75,000 - $99,999	21,241 (22.6)	441 (22.9)
$100,000 - $124,999	15,614 (16.6)	384 (19.9)
$125,000+	11,962 (12.8)	285 (14.8)
Unknown/No SES	10,543 (11.2)	180 (9.3)

(continued)

Table 1 (continued): Characteristics of study sample stratified by older sibling ASD status

	Older sibling without ASD (N=93,798) N (%)	Older sibling with ASD (N=1,929) N (%)
Maternal/paternal education		
Less than 12th Grade	946 (1.0)	10 (0.5)
High School Diploma	23,141 (24.7)	392 (20.3)
Some college/Associate Degree	45,654 (48.7)	972 (50.4)
Bachelor Degree or Higher	22,495 (24.0)	533 (27.6)
Unknown/No SES/No parents identified	1,562 (1.7)	22 (1.1)
Presence of seizures[1]	2,272 (2.4)	73 (3.8)
Presence of vaccination-associated allergies[1]	394 (0.4)	9 (0.5)
Pre-term birth[1]	7,428 (7.9)	179 (9.3)
Mental health benefit during at least first 5 years of enrollment	81,660 (87.1)	1,685 (87.4)
	Mean (SD)	**Mean (SD)**
Length of continuous enrollment (years)	7.1 (1.7)	7.2 (1.7)
Modified childhood chronic conditions score[2]	0.3 (0.6)	0.3 (0.6)
Maternal age at index child birth	32.8 (4.6)	33.5 (4.3)
Paternal age at index child birth	34.9 (5.1)	35.8 (4.8)

[1]Seizures and allergies are measured using each index child's enrollment period from birth to 24 months and preterm birth is measured using each index child's entire enrollment period from birth to disenrollment

[2] The possible range of scores for the modified childhood chronic conditions score was 0 to 9. A higher score indicates increasing clinical complexity or comorbidity.

Table 2. Unadjusted[1] and adjusted[2] MMR vaccination and ASD relative risk (RR) estimates at ages 2, 3, 4 and 5 years in children with older siblings with and without ASD diagnosed

		Older sibling without ASD (N=93,798)								Older sibling with ASD (N=1,929)							
				Unadjusted[1]			Adjusted[2]					Unadjusted[1]			Adjusted[2]		
	MMR	N[4]	ASD cases	RR	(95% CI)	p-val[3]	RR	(95% CI)	p-val	N[4]	ASD cases	RR	(95% CI)	p-val[3]	RR	(95% CI)	p-val
Age 2	One dose	77822	53	0.80	(0.44,1.47)	0.58	0.91	(0.67,1.20)	0.50	1394	7	0.44	(0.15,1.29)	0.22	0.76	(0.49,1.18)	0.22
	Unvaccinated	15249	13	ref			ref			520	6	ref			ref		
Age 3	One dose	79666	239	0.85	(0.62,1.18)	0.37	0.97	(0.78,1.20)	0.76	1458	38	0.67	(0.38,1.18)	0.21	0.81	(0.54,1.20)	0.29
	Unvaccinated	12853	45	ref			ref			438	17	ref			ref		
Age 4	One dose	79691	395	0.91	(0.70,1.18)	0.53	1.03	(0.81,1.32)	0.81	1491	64	0.67	(0.42,1.04)	0.10	0.86	(0.58,1.29)	0.46
	Unvaccinated	11957	65	ref			ref			387	25				ref		
Age 5	Two doses	45568	244	0.74	(0.55,0.99)	0.05	1.12	(0.78,1.59)	0.55	796	30	0.44	(0.26,0.75)	<0.01	0.56	(0.31,1.01)	0.05
	One dose	40495	339	1.16	(0.87,1.53)	0.35	1.10	(0.76,1.54)	0.58	864	51	0.69	(0.43,1.11)	0.16	0.92	(0.58,1.44)	0.71
	Unvaccinated	7735	56	ref			ref			269	23	ref			ref		

[1] Cumulative incidence rate ratio based on simple incidence proportions.

[2] Hazard rate ratio from Cox proportional hazards model adjusting for length of continuous enrollment, birth year, gender, region, race/ethnicity, maternal/paternal education level, household income, maternal/paternal age at index child's date of birth, Childhood Chronic Conditions score, preterm birth, seizure, allergies.

[3] Yates-corrected χ^2 test

[4] The 'N' and 'ASD cases' will not add up to the total N and ASD cases described in the results section since some children were diagnosed with ASD after age 5 and some children received 2 MMR doses prior to the recommended ages displayed.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Mon, 16 Mar 2015 12:13:16 +0000
To: Ikeda, Robin (CDC/ONDIEH/OD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Cc: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper
Attachments: VAX PAPER master final march7.docx

FYI

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From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Monday, March 16, 2015 1:58 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper

Hi Coleen,
I assume you have seen this.
Marshalyn

From: Chan, C. Leah (CDC/ONDIEH/NCBDDD)
Sent: Friday, March 13, 2015 6:55 PM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD)
Cc: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Subject: FW: NIMH MMR vaccine and autism paper

FYI—there's an NIMH-funded paper coming out soon about the MMR vaccine and autism. Please see attached.

From: Pryzby, Rachel (CDC/OID/NCEZID) (CTR)
Sent: Friday, March 13, 2015 5:55 PM
To: Chan, C. Leah (CDC/ONDIEH/NCBDDD)
Subject: NIMH MMR vaccine and autism paper

Hey Leah,

I wanted to give you a heads up that there's an NIMH-funded paper coming out soon about MMR vaccine and autism. The findings are unsurprising (vaccines *still* do not cause autism!), but HHS thinks it might get some media attention because of the measles outbreak.

Since this is NIMH's paper, we won't need to develop talking points or anything like that. But I am going to coordinate with NIMH to make sure our messaging is in sync. I will loop you in once I hear from them.

Thanks! Have a great weekend.

Rachel

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Note: I telework Wednesdays, Fridays, and every other Monday. I can be reached by email or cell (b)(6)

Title page:

Autism occurrence by MMR vaccine status among US children with older siblings with and without autism

Authors: Anjali Jain, MD, Jaclyn Marshall, MS, Ami Buikema, MPH, Tim Bancroft, PhD, Jonathan P. Kelly, MPP, Craig J. Newschaffer, PhD

Affiliations: Dr. Jain, Ms. Marshall, and Mr. Kelly are affiliated with The Lewin Group, Falls Church, VA. Ms. Buikema and Dr. Bancroft are affiliated with Optum, Eden Prairie, MN. Dr. Newschaffer is affiliated with the A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA.

Word Count: 3500

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Date of revision: March 7, 2015

Abstract

Importance: Despite research showing no link between measles-mumps-rubella (MMR) vaccine and autism spectrum disorders (ASD), beliefs that the vaccine causes autism persist, leading to lower vaccination levels. Parents who already have a child with ASD may be especially wary of vaccinations.

Objective: To report ASD occurrence by MMR vaccine status in a large sample of US children who have older siblings with and without ASD.

Design, setting, participants: A retrospective observational cohort study using an administrative claims database associated with a large commercial health plan, 1997-2012. Participants included children continuously enrolled in the health plan from birth to at least 5 years of age during 2001-2012 who also had an older sibling continuously enrolled for at least 6 months between 1997 and 2012.

Exposures: MMR vaccine receipt (0, 1, 2 doses) between birth and 5 years of age.

Main outcome measure: ASD status defined as two claims with a diagnosis code in any position for Autistic Disorder, other specified Pervasive Developmental Disorder (PDD), including Asperger's disorder, or unspecified PDD (ICD-9-CM 299.0x, 299.8x, 299.9x).

Results: Of 95,727 children with older siblings, 1,929 (2%) had an older sibling with ASD. Among children who had an older sibling with ASD, MMR vaccine receipt was not associated with an increased risk of ASD at any age. At age 2, the adjusted relative risk (RR) =0.76 (95% CI 0.49, 1.18; p=0.22), and at age 5, the RR=0.56 (95% CI 0.31, 1.01; p=0.05). Among children whose older siblings did not have ASD, MMR vaccine was also not associated with an increased risk of ASD at any age. At age 2, the RR=0.91 (95% CI 0.67, 1.20; p=0.50) and at age 5, the RR=0.74 (95% CI 0.55, 0.99; p=0.05).

Conclusions and Relevance: In this large sample of privately insured children with older siblings, receipt of MMR vaccine was not associated with increased risk of ASD regardless of whether older siblings had or did not have ASD. These findings indicate no association between MMR vaccine receipt and ASD even among children already at higher risk for ASD by virtue of having an older sibling with ASD.

Introduction

Two doses of measles-mumps-rubella (MMR) vaccine are currently recommended for children in the US: the first at 12-15 months of age and the second at 4-6 years.[1] While a substantial body of research over the last 15 years has found no link between the MMR vaccine and autism spectrum disorders (ASD),[2,3,4] parents and others continue to associate the vaccine with ASD.[5] Parents cite vaccinations, especially MMR, as a cause of ASD,[6] and have deferred or refused vaccinations for their children as a result.[7,8] Lower vaccination levels threaten public health by reducing both individual and herd immunity and have been associated with several recent outbreaks of measles, with most cases occurring among the unvaccinated.[9]

Families with a child affected by ASD may be particularly concerned about reports linking MMR and ASD, despite the lack of evidence.[10] Surveys of parents who have children with ASD suggest that many believe vaccination was a contributing cause.[11] This belief, combined with knowing that younger siblings of children with ASD are already at higher genetic risk for ASD compared to the general population,[12,13,14] might prompt these parents to avoid vaccinating their younger children. In a recent survey of 486 parents of children with ASD nearly 20% had declined or delayed MMR immunization in the younger siblings of children with ASD.[15] Furthermore, a Canadian study of 98 younger siblings of children with ASD found that younger siblings were less likely to be fully MMR-immunized compared to their older siblings with ASD. However, there were no statistically significant differences in rates of ASD diagnosis between immunized and non-immunized children.[10] To our knowledge, this very small study is alone in examining MMR immunization and ASD outcomes among the younger siblings of children with ASD.

Thus, we set out to report on ASD occurrence by MMR vaccine status in a large sample of US children having older siblings with ASD and to compare findings to those among children who have older siblings without ASD.

Methods

A retrospective cohort study was conducted using an administrative claims database associated with a large, US health plan (the Optum Research Database, or ORD). The ORD includes more than 34 million individuals each year, containing both commercially-insured individuals and Medicare Managed Care enrollees. The database consists of proprietary, de-identified health claims data from a geographically diverse US population (16% West, 20% Midwest, 36% South, and 27% Northeast). In addition, the age and gender distribution of the enrollees is similar to that reported by the US Census Bureau for the commercially insured and the Medicare Managed Care population. The New England Institutional Review Board waived the need for informed consent and deemed the study exempt under category E for the study of existing, de-identified[16] data in November 2013.

Index children were identified among commercially-insured enrollees who had both medical and pharmacy coverage and included all children in the database born between 01 January 2001 and 31 December 2007 who were continuously enrolled in the health plan from birth to at least 5 years of age and who also had an older sibling continuously enrolled in the health plan for at least 6 months between the beginning and end of the study period, 1 January 1997 through 31 December 2012. Older siblings of index children were identified using a family identifier variable associated with the insurance policy; siblings had to be between 0.5-17 years older than the index child to be included.

ASD status in index children and older siblings was determined using a claims-based algorithm[17] that required two or more claims on separate dates of service with an ICD-9 diagnosis code in any

position for: Autistic Disorder, other specified Pervasive Developmental Disorder (PDD), including Asperger's disorder, or unspecified PDD (299.0x, 299.8x, and 299.9x). Both index child and older sibling ASD status were determined using their entire enrollment time that fell within the study period. Index children had to have at least one older sibling with two claims with ASD diagnoses, or all older siblings with no ASD diagnoses. Children with an older sibling with only one diagnosis of ASD were excluded. Index children with only one diagnosis of ASD were also excluded.

MMR vaccine receipt was defined as having a Current Procedural Terminology (CPT) or International Classification of Diseases, Ninth Revision (ICD-9) procedure code indicating receipt of each component (M, M, and R) between birth and five years of age (see eTable 2). The date of administration of the trivalent MMR (or the last-administered component of monovalent vaccines) was used to determine age at administration for each dose (first or second).

Because the recommended age of first MMR dose administration is 12 to 15 months, and 4 to 6 years for the second dose, relative risks (RRs) were estimated to compare ASD status in children receiving one-dose of MMR at ages 2, 3, 4 and 5, and two-doses at age 5 to those who were unvaccinated at those ages (two dose RRs at age 4 would only include those children who received the second dose by their 4^{th} birthday). Separate RRs were estimated for children with older siblings with and without ASD. Since no subjects were lost to follow-up before age 5, unadjusted RRs were reported as cumulative incidence rate ratios, calculated simply by taking the ratio of the proportion of subjects who had an ASD diagnosis in an exposed group (either one MMR dose or two MMR doses) to the proportion of subjects who had an ASD diagnosis in the unvaccinated group at a given age.

Adjusted RRs were reported as hazard rate ratios estimated from a single Cox proportional hazard regression model that used age since birth as the time-scale and included MMR receipt as a time-varying covariate ascribing follow-up time to either the unvaccinated group, the one-dose

group, or the two-dose group depending on immunization status at any given age. An interaction term between MMR receipt and older sibling ASD status was included to all adjusted RRs to vary by older sibling ASD status. In addition, interactions between MMR receipt and age (to relax the proportionality assumption and allow hazard ratios (HRs) to vary by age) as well as a three-way interaction between MMR receipt, age, and older sibling ASD status were tested for possible inclusion in the final model.

Both time-varying and fixed covariates were also included in adjusted models to control for potential confounding. Separate claims-based indicators of the presence of seizures and vaccine-related allergies in the index child were included as time-varying covariates because they are possible contraindications to vaccines and are, or are potentially, associated with ASD status.[18,19,20] To capture aspects of the index child's overall health status that might also be associated with both MMR receipt and ASD status, an indicator for preterm birth and a modified, claims-based version[21] of the childhood chronic conditions score (CCC)[22] were included as fixed covariates. The modified CCC uses claims-based diagnosis codes to capture the presence of chronic conditions, excluding those associated with ASD, within nine domains: 1) neuromuscular, 2) cardiovascular, 3) respiratory, 4) renal, 5) gastrointestinal, 6) hematologic or immunologic, 7) metabolic, 8) other congenital or genetic defects, and 9) malignant neoplasms. The presence of at least one claim for a condition within each domain between birth and age 2 adds one point to the CCC score, which ranges from 0 to 9. See eTable 3 for ICD-9 codes used to define conditions and variables.

Maternal/paternal educational level, household income, and race/ ethnicity were also included as fixed covariates. These sociodemographic factors have been associated with both ASD status[23] and vaccine receipt.[24] Approximately 30% of the race/ethnicity data in this study were collected directly from public records (e.g. driver's license records), while the remaining data were imputed using commercial software (E-Tech by Ethnic Technologies LLC. South Hackensack, NJ) that

uses algorithms developed with Census data ZIP codes (ZIP+4) and first and last names. This imputation method has been validated and demonstrates 97% sensitivity, 48% specificity and 71% positive predictive value for estimating the race of Black individuals.[25] Individuals categorized as "other/unknown" for race/ethnicity were those whose race/ethnicity could not be assigned by the imputation algorithm or who were added to the dataset after the imputation had been performed.

Other fixed covariates included in the adjusted models were index child gender, mother's and father's age at index child's birth, geographic location defined by the four US Census regions, mental health benefits, and index child birth year which was included to adjust for varying opportunity to develop/diagnose ASD. Response categories were created for unknown or missing values of all covariates and included as such in regression models.

A series of sensitivity analyses were conducted to explore the influence of potential MMR or ASD status measurement error on results. Quantitative bias analyses were implemented for both exposure and outcome misclassification following the approach described in Lash et al (2009.[26] More detail on bias analysis methods are provided in the online-only supplement (See "Sensitivity Analyses for Exposure and Outcome Misclassification" and eTable 1). In addition, associations between MMR receipt and ASD risk were also re-estimated using a less-restrictive one-claim criterion for ASD diagnosis in younger siblings. Finally, an additional sensitivity analysis was also performed rerunning final models on the subset of subjects with no missing data on any covariates.

Two-sided statistical significance testing of unadjusted rate ratios was conducted using Yates chi-squared test and two-sided statistical significance testing of hazard ratios estimated by maximum likelihood were conducted using Wald chi-squared statistics. Likelihood ratio tests were used to

test the significance of Cox proportional hazards models with and without interaction terms. The alpha level for all tests was 0.05. Analyses were performed in SAS 9.2 (SAS Institute, Cary NC).

Results

Out of 95,727 children in the cohort, 1,929 (2%) had an older sibling with ASD. Overall, 994 (1%) children in the cohort had ASD diagnosed during follow-up. Among those who had an older sibling with ASD, 134 (6.9%) were diagnosed with ASD, compared to 860 (0.9%) diagnosed with ASD among those with siblings without ASD (6.9% vs. 0.9%, $p<0.001$). The MMR vaccination rate (at least one dose) for the children with unaffected siblings (siblings without ASD) was 84% at 2 years and 92% at age 5. In contrast, the MMR vaccination rates for children with older siblings with ASD were markedly lower - 73% at age 2 and 86% at age 5.

Table 1 shows the clinical and socio-demographic characteristics of the 95,727 children stratified by older sibling ASD status. Birth years were roughly equally distributed over 2001-2007, and a little more than half the sample was male. About three quarters were white; blacks were underrepresented at ~3% (compared to 13% in the U.S. population) and Hispanics made up ~9% (compared to 17% in the U.S. population).[27] All four of the major geographic regions in the US were represented, with somewhat more representation in the south (42% vs. 38%) and less in the west (17% vs. 24%) as compared to the overall U.S. population.[27] About 3% had a potential contraindication to vaccine receipt and about 8% were preterm. The average length of continuous enrollment was just over 7 years.

Table 2 includes unadjusted relative risks of ASD (cumulative incidence rate ratios) associated with receiving either one MMR dose or two MMR doses (compared to no doses) at ages 2, 3, 4 and 5 years separately in children with and without older siblings who have ASD. The unadjusted RR for one dose of MMR at age 2 years among children with unaffected older siblings was 0.80 (95% CI 0.44, 1.47; p=0.58) and 0.44 (95% CI 0.15, 1.29; p=0.22) among children with older

siblings with ASD. Similarly, at ages 3, 4 and 5, no association was found between one dose of MMR and ASD among index children, irrespective of whether their older siblings had ASD. For two doses of MMR at age 5 years, the unadjusted RR was 0.74 (95% CI 0.55, 0.99; p=0.05) among children with unaffected older siblings and 0.44 (95% CI 0.26, 0.75; p<0.01) among children with older siblings with ASD.

Table 2 also shows adjusted RRs (hazard rate ratios) estimated from the Cox proportional hazards model. Interactions between MMR receipt and older sibling ASD status as well as MMR receipt and younger sibling age both significantly improved the fit of a base main effects only model (p=0.048, and p=0.015, respectively) and were thus retained in the final model. The addition of the three-way interaction between MMR receipt, age, and older sibling ASD status provided no additional improvement in model fit (p=0.382) and was not retained.

In general, adjusted one-dose RR estimates were closer to the null than unadjusted estimates and none of the one-dose RR estimates at any age were statistically significant. The adjusted RRs for one dose of MMR at age 2 years was 0.91 (95% CI 0.67, 1.20; p=0.50) among children with unaffected older siblings and 0.76 (95% CI 0.49, 1.18; p=0.22) among children with older siblings with ASD. At five years the adjusted RRs for one dose of MMR were 1.10 (95% CI 0.76, 1.54; p=0.58) and 0.92 (95% CI 0.58,1.44; p=0.71), respectively. There appeared to be a similar influence of adjustment on the two-dose RR estimates, although the RR estimate in children with affected older siblings approached statistical significance. These adjusted RRs were 1.12 (95% CI 0.78, 1.59; p=0.55) and 0.56 (95% CI 0.31, 1.01; p=0.05) in children without and with affected older siblings respectively.

Quantitative bias analysis suggested that the influence of potential under-reporting of MMR immunization in our claims data on RR estimates would be modest and toward the null. Non-differential outcome misclassification, if present, would appear to have a very small additional

biasing effect toward the null. Differential outcome misclassification, if present, would most likely manifest as greater outcome detection sensitivity among those vaccinated then among those not vaccinated, would make actual RRs smaller than those reported. These bias analyses are informative, but need to be cautiously interpreted given the assumptions involved. More detail is provided in the online-only supplement.

In other sensitivity analyses, we saw that results were not substantively different in Cox models that used the presence of just one claim with ASD to define outcome (see eTable 4). In addition, the original Cox model was rerun excluding the 19% of the sample that was missing some sociodemographic data, again, results were not substantially changed (see eTable 5).

Comment

Consistent with studies in other populations,[2,3,4] we observed no association between MMR vaccination and ASD risk among privately insured children. We also found no evidence that receipt of either one or two doses of MMR vaccination was associated with an increased risk of ASD among children who had older siblings with ASD, a group of children who are particularly important as they are often under-vaccinated in our observations as well as in previous reports.[10,15]

Although we did not see any statistically significant relative risk estimates indicating increased ASD risk at any age in either group of children—those whose older siblings had or did not have ASD—the statistically significant interactions in the final Cox model suggests differences in relative risk by both age and older sibling ASD status. The pattern in relative risks across these groups was such that lower RR estimates (commonly extending into the protective range, i.e.,below 1.0) were observed at younger vs. older ages and in children with older siblings with vs. without ASD. Although protective estimates tended not to reach statistical significance, this pattern is worth further consideration. It is possible, for example, that this pattern is driven by selective parental decision-making around MMR immunization where parents who notice social

or communication delays in their children decide to forestall vaccination. Because, as a group, children with recognized delays are likely to be at higher risk of ASD, such selectivity could result in a tendency for some higher risk children to be unexposed. To be consistent with observed data, this would need to happen more often at younger ages. This seems feasible because, by the time the child is older, developmental concerns are more likely to have been confirmed or ruled out and parents may then be less worried about a new exposure—such as a vaccination—influencing a child's developmental trajectory. Estimates at older ages would thus be less susceptible to bias related to selective parental decision-making, which also aligns with the pattern observed here. This explanation would also suggest that the estimate for the one-dose RR estimate at age 5 (1.10; 95% CI 0.76, 1.54) is least vulnerable to this bias because age 5 is several years removed from the time parents are typically deciding about the first MMR dose or weighing the importance of early developmental concerns.

We also saw this tendency toward lower RR estimates for children whose older siblings had ASD, compared to those with unaffected older siblings. As seen in our data and other studies,[10,15] MMR immunization is lower in children with older siblings with ASD. It is also plausible that parents of affected older siblings would be especially attentive to developmental delays in their younger children and decide to forestall immunization. Among the younger siblings of children with ASD who were vaccinated with MMR, 38% of older siblings had their first ASD claim prior to the younger sibling's vaccination whereas more than half of the younger siblings of children with ASD who were not vaccinated had older siblings with an ASD claim by the time the younger sibling was due to receive MMR (data not shown). In other words, if the older sibling's ASD was known when MMR was due, vaccination was less likely in the younger sibling. Of course, developmental abnormalities in affected older siblings may also have appeared and raised parental concerns prior to encounters generating ASD claims. Note also that the contrast in relative risks between children with and without older ASD- affected siblings is most dramatic for

two doses at age 5; the ratio of the adjusted estimates at this age being 2.0 (1.12 / 0.56) for two doses compared to 1.19 (1.12 / 0.56) for one dose. This could reflect more older siblings being confirmed as having ASD between the younger siblings' recommended ages of first and second dose administration, potentially leading parents to raise de novo concerns about the vaccine's safety at the time second dose decisions are being made.

This study used a large administrative claims dataset spanning a recent 11-year period to examine associations between MMR immunization status and ASD risk in the US. The administrative claims database allowed for the prospective estimation of associations free from potential recall bias. However, administrative claims data do present some important research limitations. Claims are generated for payment, so diagnoses and procedures that don't affect payment are likely under-reported, diagnosis for conditions that may eventually be ruled out can be over-reported, and procedures and services that individuals receive through other payers may not be captured. We conducted a series of quantitative bias analyses to assess the potential impact of this measurement error and do not believe these are strongly influencing our findings. There are also potential inaccuracies in the identification of siblings from claims because of assumptions made about family relationships among individuals on the same health plan. However these are unlikely to be systematically related to either immunization status or ASD diagnosis.

For children born after a hypothetical link between MMR and autism risk was introduced, parental suspicion of developmental delay could influence MMR immunization decision-making. While the extent of this phenomenon is unknown, its existence is one explanation for the pattern of some of the RRs observed here. However, at ages and doses where this phenomenon would be least likely to be operating, there is no evidence of an association between MMR and autism risk.

Finally, these data and results are based on privately insured children with an extensive period – 5 years – of continuous enrollment in a single health plan and may not be completely generalizable

to other groups. The prevalence of ASD among all index children in the study sample was 1%, comparable to the current estimate of ASD prevalence of 1.5% in the general US population.[28] In addition, the younger siblings of children with ASD had a 6.9% risk of ASD themselves, also consistent with published estimates ranging from 6.4 to 24.7%.[12,13,14] Our findings may not be as applicable to more ethnically and socioeconomically diverse populations who have less access to health care services. For example, in our population the average age of ASD recognition based on claims was 4 years, several months earlier than the average age of ASD diagnosis in the US of 4 years, 5 months.[28]

Conclusion

In this large sample of privately insured children with older siblings, receipt of MMR vaccine was not associated with increased risk of ASD regardless of whether older siblings had or did not have ASD. These findings indicate no association between MMR vaccine receipt and ASD even among children already at higher risk for ASD by virtue of having an older sibling with ASD.

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Table 1: Characteristics of study sample stratified by older sibling ASD status

	Older sibling without ASD (N=93,798) N (%)	Older sibling with ASD (N=1,929) N (%)
Birth year		
2001	11,292 (12.0)	188 (9.7)
2002	11,541 (12.3)	213 (11.0)
2003	12,194 (13.0)	239 (12.4)
2004	12,587 (13.4)	253 (13.1)
2005	14,121 (15.1)	325 (16.8)
2006	15,316 (16.3)	349 (18.1)
2007	16,747 (17.9)	362 (18.8)
Gender		
Male	47,917 (51.1)	975 (50.5)
Female	45,881 (48.9)	954 (49.5)
Geographic region		
Northeast	10,281 (11.0)	279 (14.5)
Midwest	27,497 (29.3)	588 (30.5)
South	39,698 (42.3)	771 (40.0)
West	16,291 (17.4)	290 (15.0)
Other	31 (<0.1)	1 (<0.1)
Race/Ethnicity		
White	68,524 (73.1)	1,509 (78.2)
African-American/Black	3,538 (3.8)	39 (2.0)
Native Hawaiian or Pacific Islander	81 (0.1)	0 (0.0)
American Indian or Alaskan Native	188 (0.2)	3 (0.2)
Asian	3,256 (3.5)	58 (3.0)
Hispanic	8,605 (9.2)	129 (6.7)
Other	1,614 (1.7)	28 (1.5)
Unknown/No SES	7,992 (8.5)	163 (8.4)
Household income		
Under $50,000	13,025 (13.9)	228 (11.8)
$50,000 - $74,999	21,413 (22.8)	411 (21.3)
$75,000 - $99,999	21,241 (22.6)	441 (22.9)
$100,000 - $124,999	15,614 (16.6)	384 (19.9)
$125,000+	11,962 (12.8)	285 (14.8)
Unknown/No SES	10,543 (11.2)	180 (9.3)

(continued)

Table 1 (continued): Characteristics of study sample stratified by older sibling ASD status

	Older sibling without ASD (N=93,798) N (%)	Older sibling with ASD (N=1,929) N (%)
Maternal/paternal education		
Less than 12th Grade	946 (1.0)	10 (0.5)
High School Diploma	23,141 (24.7)	392 (20.3)
Some college/Associate Degree	45,654 (48.7)	972 (50.4)
Bachelor Degree or Higher	22,495 (24.0)	533 (27.6)
Unknown/No SES/No parents identified	1,562 (1.7)	22 (1.1)
Presence of seizures[1]	2,272 (2.4)	73 (3.8)
Presence of vaccination-associated allergies[1]	394 (0.4)	9 (0.5)
Pre-term birth[1]	7,428 (7.9)	179 (9.3)
Mental health benefit during at least first 5 years of enrollment	81,660 (87.1)	1,685 (87.4)
	Mean (SD)	**Mean (SD)**
Length of continuous enrollment (years)	7.1 (1.7)	7.2 (1.7)
Modified childhood chronic conditions score[2]	0.3 (0.6)	0.3 (0.6)
Maternal age at index child birth	32.8 (4.6)	33.5 (4.3)
Paternal age at index child birth	34.9 (5.1)	35.8 (4.8)

[1]Seizures and allergies are measured using each index child's enrollment period from birth to 24 months and preterm birth is measured using each index child's entire enrollment period from birth to disenrollment

[2] The possible range of scores for the modified childhood chronic conditions score was 0 to 9. A higher score indicates increasing clinical complexity or comorbidity.

Table 2. Unadjusted[1] and adjusted[2] MMR vaccination and ASD relative risk (RR) estimates at ages 2, 3, 4 and 5 years in children with older siblings with and without ASD diagnosed

		Older sibling without ASD (N=93,798)								Older sibling with ASD (N=1,929)							
				Unadjusted[1]			Adjusted[2]					Unadjusted[1]			Adjusted[2]		
	MMR	N[4]	ASD cases	RR	(95% CI)	p-val[3]	RR	(95% CI)	p-val	N[4]	ASD cases	RR	(95% CI)	p-val[3]	RR	(95% CI)	p-val
Age 2	One dose	77822	53	0.80	(0.44,1.47)	0.58	0.91	(0.67,1.20)	0.50	1394	7	0.44	(0.15,1.29)	0.22	0.76	(0.49,1.18)	0.22
	Unvaccinated	15249	13	ref			ref			520	6	ref			ref		
Age 3	One dose	79666	239	0.85	(0.62,1.18)	0.37	0.97	(0.78,1.20)	0.76	1458	38	0.67	(0.38,1.18)	0.21	0.81	(0.54,1.20)	0.29
	Unvaccinated	12853	45	ref			ref			438	17	ref			ref		
Age 4	One dose	79691	395	0.91	(0.70,1.18)	0.53	1.03	(0.81,1.32)	0.81	1491	64	0.67	(0.42,1.04)	0.10	0.86	(0.58,1.29)	0.46
	Unvaccinated	11957	65	ref			ref			387	25				ref		
Age 5	Two doses	45568	244	0.74	(0.55,0.99)	0.05	1.12	(0.78,1.59)	0.55	796	30	0.44	(0.26,0.75)	<0.01	0.56	(0.31,1.01)	0.05
	One dose	40495	339	1.16	(0.87,1.53)	0.35	1.10	(0.76,1.54)	0.58	864	51	0.69	(0.43,1.11)	0.16	0.92	(0.58,1.44)	0.71
	Unvaccinated	7735	56	ref			ref			269	23	ref			ref		

[1] Cumulative incidence rate ratio based on simple incidence proportions.

[2] Hazard rate ratio from Cox proportional hazards model adjusting for length of continuous enrollment, birth year, gender, region, race/ethnicity, maternal/paternal education level, household income, maternal/paternal age at index child's date of birth, Childhood Chronic Conditions score, preterm birth, seizure, allergies.

[3] Yates-corrected χ^2 test

[4] The 'N' and 'ASD cases' will not add up to the total N and ASD cases described in the results section since some children were diagnosed with ASD after age 5 and some children received 2 MMR doses prior to the recommended ages displayed.

(b)(6) ; (b)(7)(C)

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(b)(6) ; (b)(7)(C)

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(b)(7)(D)

(b)(7)(D)

(b)(7)(D)

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(b)(7)(D)

(b)(7)(D)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 13 Jan 2015 14:38:21 +0000
To: Ghosh, Sudevi (CDC/OCOO/OGC)
Subject: FW: Reanalysis of the DeStefano et al (2004) MMR-Autism Study data

fyi

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
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Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Monday, January 12, 2015 1:29 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID)
Cc: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Rick Morgan (b)(6)
Subject: Reanalysis of the DeStefano et al (2004) MMR-Autism Study data

Coleen, Marshalyn, & Frank

I plan to submit a new manuscript for publication regarding MMR-Autism associations based on reanalysis of the dataset from our 2004 study. My choices are to publish results from the previous analyses that we ran as part of our previous published manuscript, or to rerun the analyses using the public use data set. I prefer the latter option, but would like to solicit your opinions.

Please let me know whether, given my previous work with the dataset, there are any procedures which I must follow to either access or utilize the public use dataset. I assume that, as is usual for CDC employees, I would not be required to follow procedures required for external researchers, which of course are set up to protect the data from being distributed externally and then misused. I am assuming

that I will only need to submit an IRB research determination form in order to move forward with the reanalysis.

Please advise.

Thanks,

--Bill

William W. Thompson, PhD
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(b)(6) (cell)
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Courier Delivery:
1825 Century Blvd., NE
MS-E86
Atlanta, GA 30345

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Thu, 29 Oct 2015 00:47:45 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

FYI

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Monday, July 06, 2015 7:12 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD) <wct2@cdc.gov>
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Schieve, Laura (CDC/ONDIEH/NCBDDD) <ljs9@cdc.gov>
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Thanks for letting me know.

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Monday, July 06, 2015 9:47 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Thanks Cindy!

I consulted with someone who has a significant amount of experience working with CDC and carrying out research as an outside activity. What I was told was to set up a Limited Liability Corporation (LLC) and to simply ask for permission to carry out research that is not funded by HHS. That protects me legally and won't require me to seek permission from you and others for outside activity research on a case by case basis. So I will take that strategy and submit the request soon.

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Sunday, July 05, 2015 4:20 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Bill,

I'm sorry to be so long in getting back with you. I've been out on leave and I understand you have also. Hope you had a good break.

In response to your question below, my answers are simply providing a clear and concise rationale to reviewers of your outside activity request regarding why we would not consider the analysis you are proposing to be part of your official duties.

I'd be happy to discuss. My calendar is usually up-to-date.

Regards,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Monday, June 08, 2015 8:10 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Cindy,

I just want to make sure we are on the same page. Are my current duties restricted to the 7 priority domains for SEED?

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Sunday, June 07, 2015 6:08 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Hi Bill,

I haven't been successful in following up with the Ethics Office so I suggest you forge ahead and we'll work on any issues if they develop. Below are my suggestions for the questions you will need to respond to in your request. I think short and to the point is the best way to answer but happy to discuss if you have other thoughts/questions.

1) For the first question related to nature of your official duties, I reviewed your PD and your PMAP. As you know, the official duties laid out in these documents are based on functions/activities of a senior epidemiologist and aren't specific to any condition(s) or research question(s). Therefore, the focus of your work is determined by program priorities.

2) For the second question about the relation of the outside activity and your official duties, I return to the first answer. The program has developed 7 priority domains of inquiry related to autism risk factors and the priority data source is SEED. For these priorities, numerous analytic projects using SEED data have been defined. The proposed reanalysis of the MMR-Autism study data falls outside these priority projects and would be considered an outside activity.

Regards,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, May 27, 2015 10:59 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Cindy,

I am attaching my current PD and my 2015 PMAS.

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, May 26, 2015 7:15 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Hi Bill,

I have asked Anita for your PD. If you have a copy to share that will speed things up.

Thanks,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, May 26, 2015 10:07 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Cindy,

Do you know when you can get me a copy of the draft text?

Thanks,

Bill

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, May 21, 2015 1:34 PM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Thanks Cindy. Just send me the draft text when you finish it and I will review it. BT

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, May 20, 2015 11:49 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Sure, I'll help. I'm not familiar with that testimony but I don't believe the original legislation specified which risk factors. I will take a look.

Just getting in from meetings at 1825 so I will try to get to this later today.

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, May 19, 2015 5:23 PM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Cindy,

I am going to take your advice and pursue the re-analysis of the MMR-Autism data as an outside activity given you have decided that it doesn't fall into my current official duties. On page 6 of the outside activities form (see attached), I have to complete sections III-1 and III-2. This requires me to 1) Describe the Nature of my Official Duties and 2) Describe the Relationship of Official Duties to the Outside Activity. This is challenging for me because according to Congressional Testimony by Roger Bernier (see attached), CADDRE was funded to examine associations between the MMR vaccine and autism.

So I have 2 questions:

1) What are the Nature of my Official Duties?
2) Are you willing to assist me in describing how the outside activity is not related to my official duties?

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Friday, February 27, 2015 12:19 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Bill,

As I've said, it's my understanding that undertaking this reanalysis would not fall into your official duties or current scope of work. Therefore, you could pursue it as an outside activity if you choose. I'm available to chat.

Thanks,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 26, 2015 10:22 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Thanks Cindy,

For now my only option is to listen to your instructions given you are in my direct chain of command. So, I am going to accept your interpretation and stop pursuing this further at this point in time.

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, February 25, 2015 1:32 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Hi Bill,

I came by your office yesterday to chat and make sure that we are on the same page re outside activities. Sorry I missed you, but in a nutshell, it's my understanding that undertaking this reanalysis would not fall into your official duties or current scope of work. Therefore, you could pursue it as an outside activity if you choose. I'm available to chat about this further or provide assistance when we are back in the office.

Thanks,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, February 24, 2015 11:00 AM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Campbell, Scott (CDC/ONDIEH/NCBDDD); Shapira, Stuart (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Thanks for the clarification Cindy.

I am cc'ing Scott & Stuart just so they know that they should not move forward on approving my request for a research determination of the public use data set.

I am assuming this activity would fall within the scope of my current job duties so it wouldn't get approved by an outside activity request. So, I don't plan on pursuing that avenue at this point in time.

Thanks,

Bill

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, February 24, 2015 9:59 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Hi Bill,

As we recently discussed, no official CDC analyses and publications from these data are being undertaken at this time. However, you may wish to pursue this as an outside activity using only the publicly available data. If you would like to do so, you will need to follow the procedures for obtaining approval of an outside activity, which you can find here: http://intranet.cdc.gov/od/hcrmo/html/ethics/outside_activities.html. The website contains helpful information about the process and requirements for undertaking outside activities. Please feel free to contact me if you have questions.

Thanks,

Cindy

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Monday, February 23, 2015 7:08 AM
To: Campbell, Scott (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Shapira, Stuart (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: Research determination form for reanalysis of NCBDDD MMR-Autism Study using the public use data set

Scott,

I am submitting my completed research determination form for your review. I will be carrying out a reanalysis of the of the MMR-Autism data using the public use data set. From my perspective, I would suggest that I am not engaged in research because I will be using the public use data set and I am just rerunning analyses that were run as part of the original study prior to the data set becoming a public use data set. No data will be sent outside the CDC and I will be doing all the statistical analyses myself.

Cindy Moore has told me she would not like me to submit anything for publication yet. Cindy is welcome to weigh in here if she will not allow me to run analyses off of the public use data set while I wait to get approval to submit a manuscript for publication. If Cindy would not like me to run and report analyses off the public use data set, then I will simply report the original analyses and results that we ran and summarized previously. I think this will probably still require you to approve the research determination form.

I know that Stuart's signature is required and just tell me who else needs to sign off.

Thanks,

Bill

William W. Thompson, PhD
Senior Scientist
National Center of Birth Defects and Developmental Disabilities
U.S. Centers for Disease Control & Prevention
1600 Clifton RD, NE
Atlanta, GA, 30333

Cell: (b)(6)
Phone: (404) 498-3845

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 10 Sep 2014 14:43:31 +0000
To: Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: FW: revised protocol for 2004 Pediatrics paper on age at MMR vaccine and autism

Coleen A. Boyle, PhD, MS hyg
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Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Weinbaum, Cindy (CDC/OID/NCEZID)
Sent: Wednesday, September 10, 2014 9:35 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: revised protocol for 2004 Pediatrics paper on age at MMR vaccine and autism

Coleen –As I mentioned, CDC HRPO did a search in their historical IRB files for a record of any similar study. All I have is a line-listing; CDC would request the IRB submission documents from the Federal Records Center. It sounded like it's likely this IRB proposal would be the same study.

2391	Study of Autism and Childhood MMR Vaccine History	CCHP/NCBDDD	**MX Y1**	**A**

Talk to you soon.

Thanks!

Cindy.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, September 10, 2014 8:32 AM
To: Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: FW: revised protocol for 2004 Pediatrics paper on age at MMR vaccine and autism
Importance: High

Hi Cindy: Pls give me a call and I will explain these two documents to you. Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, September 09, 2014 1:50 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: revised protocol for 2004 Pediatrics paper on age at MMR vaccine and autism
Importance: High

Call when you can, thanks, b

From: Weinbaum, Cindy (CDC/OID/NCEZID)
Sent: Tuesday, September 09, 2014 1:48 PM
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: FW: revised protocol for 2004 Pediatrics paper on age at MMR vaccine and autism
Importance: High

Betsy,

These were the versions I forwarded to OGC – dated May 11th, 2001 and Sept 5th, 2001.
Thanks for figuring out which was IRB-approved.
Cindy.

From: Weinbaum, Cindy (CDC/OID/NCEZID)
Sent: Tuesday, September 09, 2014 12:12 PM
To: Malone, Kevin M. (CDC/OCOO/OGC); Ford, Kenya S. (CDC/OCOO/OGC)
Cc: Brower, Melissa (CDC/OID/NCEZID); Beltrami, Elise MD (CDC/OID/NCEZID); Lucido, Sal (CDC/ONDIEH/NCBDDD)
Subject: (b)(5)
Importance: High

Kevin, Kenya,

(b)(5)

Thanks very much for your help!

Cindy.

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, September 09, 2014 11:47 AM
To: Reynolds, Barbara S. (CDC/OD/OADC)
Cc: Gonzalez, Belsie (CDC/OD/OADC); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: FW: revised
Importance: High

Correction—see attached. b

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, September 09, 2014 11:46 AM
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: revised

This is the original one sent to reviewers.

Coleen A. Boyle, PhD, MS hyg
Director

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From: Reott, Erica (CDC/ONDIEH/NCBDDD)
Sent: Thu, 14 May 2015 10:17:03 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: Suspected Risk Factor List - ASD
Attachments: Research Priorities for Determining Risk Factors for ASD.docx, autismSLIDE.pptx

Got this and am working on adding out some additional references – will send you an updated copy shortly and we can discuss anything else we should modify before sending to IA

From: Schieve, Laura (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, May 13, 2015 4:29 PM
To: Reott, Erica (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Cc: Schieve, Laura (CDC/ONDIEH/NCBDDD)
Subject: FW: Suspected Risk Factor List - ASD

(b)(5)

I need to sign off for the evening.

Laura

(b)(5)

(b)(5)

From: Reott, Erica (CDC/ONDIEH/NCBDDD)
Sent: Monday, April 27, 2015 5:15 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: RE: Suspected Risk Factor List - ASD

Hi all –

(b)(5)

Erica

From: Reott, Erica (CDC/ONDIEH/NCBDDD)
Sent: Friday, April 10, 2015 10:10 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: Suspected Risk Factor List - ASD

Good morning all and happy Friday!

Please find attached an initial take on a Suspected Risk Factor list. Please email your edits/comments back and/or come prepared to discuss at our next meeting (Shakia will shortly be sending out a calendar invite for a recurring meeting for this group as well.)
<< File: Suspected Risk Factors for ASD boyle.docx >>

Thanks,
ER

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From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 9 Sep 2014 14:02:12 +0000
To: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: Tune in! "Vaccines - Calling the Shots" Tomorrow on PBS

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Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Autism Science Foundation [mailto:contactus@autismsciencefoundation.org]
Sent: Tuesday, September 09, 2014 10:01 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Tune in! "Vaccines - Calling the Shots" Tomorrow on PBS

Having trouble viewing this email? Click here

September 9, 2014

IN THIS ISSUE

Tune in to Watch *Vaccines - Calling the Shots* Tomorrow at 9pm ET/8CT on PBS

Science Workshop: Sex and Gender Differences in ASD

Support ASF with AmazonSmile

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Diseases that were largely eradicated in the United States a generation ago - whooping cough, measles, mumps - are returning, in part because nervous parents are skipping their children's shots. Parents' concerns are often due to fears associated with autism even though dozens of studies have shown no link between the two.

NOVA's *Vaccines - Calling the Shots* takes viewers around the world to track epidemics, explore the science behind vaccinations, hear from parents wrestling with vaccine-related questions, and shed light on the risks of opting out.

Autism Science Foundation president Alison Singer, ASF board member Dr. Paul Offit and Dr. Dan Geschwind of UCLA are featured in the new PBS NOVA program. ASF Scientific Advisory Board member Dr. Joseph Buxbaum served as an advisor to the program's producers. Be sure to tune in to **PBS tomorrow night at 9pm ET/8C**.

Click here to watch a short preview of Vaccines - Calling the Shots.

Research Enhancement Mini-Grants Due September 12

There are just a few days left to submit your application for this year's Research Enhancement Mini-Grants! These are grants of up to $5000 to expand the scope and increase the efficiency of active autism research grants. Applications must be received by **September 12, 2014** and awards will be announced in mid-fall.

For complete information about Mini-Grants, please click here.
To view the recipients of last year's Mini-Grants, please click here.

Predoctoral, Postdoctoral, and Medical School Gap Year Training Awards Conference Call

Are you planning to apply for an ASF Pre- or Postdoctoral Training Award or a Medical School Gap Year Award? There will be an optional informational conference call on **September 15 at 12:00pm ET** where we will share best practices for completing the application. Participation on the conference call is NOT required for application.

The call in number is 866-906-9888 and the participant code is 2574613#.

Applications must be received by November 14, 2014. Awards will be announced in March 2015 for projects beginning July-September 2015.

Additional information about this RFA can be found here.

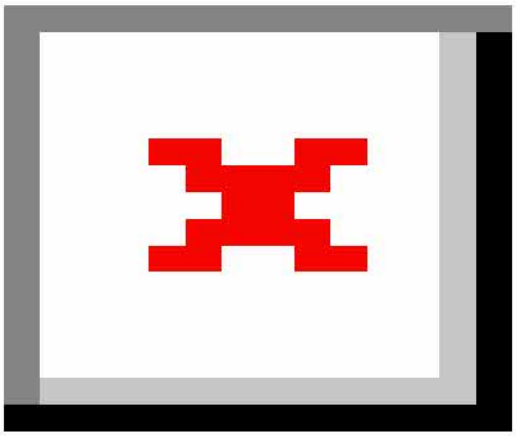
IACC Workshop: Under-Recognized Co-Occurring Conditions in Autism Spectrum Disorder

Please join us for the IACC Workshop on Under-Recognized Co-Occurring Conditions in Autism Spectrum Disorder that will take place on **Tuesday, September 23, 2014, 9am to 5pm ET in Bethesda, Maryland.**

This event will focus on a range of co-occurring health conditions in individuals with ASD that are under-recognized in clinical and services settings, as well as how to best support both research and increased community/provider awareness of these conditions and foster development of guidelines in areas that are currently under-recognized.

For more information about the workshop, including how to register, click here.

Science Workshop: Sex and Gender Differences in Autism Spectrum Disorder

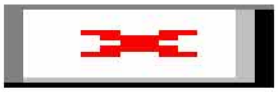


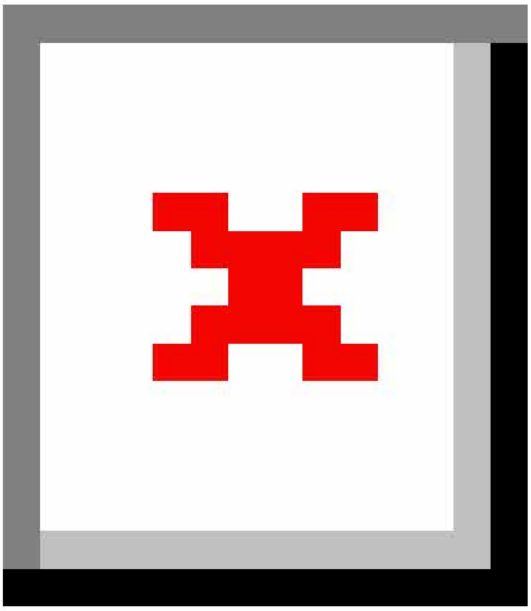
This workshop is sponsored by the Autism Science Foundation and Autism Speaks, and will focus on:
Behavioral features: What do girls "look" like?
Society and culture: How are girls with autism treated?
Diagnosis and disparity issues: Are girls underdiagnosed?
Causes of the disparity: Are females "protected" in some way?
Developmental trajectory: When do symptoms develop in girls and boys?

Advance registration is required and seating is limited.
To register, email Meredith Gilmer: mgilmer@autismsciencefoundation.org

Support ASF When You Shop on Amazon!

Did you know that you can support ASF every time you shop online at Amazon.com? Through the AmazonSmile program, you pay the same price for your items and Amazon donates 0.5% of the purchase price to ASF. To sign up, go to smile.amazon.com and choose to support the Autism Science Foundation. Now when you shop, you'll also be donating to autism research!





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Autism Science Foundation | 28 West 39th Street | New York | NY | 10018

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 20 Aug 2014 21:39:02 +0000
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: FW: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)
Attachments: Talking points_Brian Hooker_MMR_Autism_8_20_2014 ISO response.docx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Cl: (b)(6)
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, August 20, 2014 5:31 PM
To: Franklin, C. Leah (CDC/ONDIEH/NCBDDD)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Fw: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)

Leah, see below, b
Betsy Mitchell
Sent from my Blackberry

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Wednesday, August 20, 2014 05:29 PM Eastern Standard Time
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa

(CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: RE: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)

Here is my draft response to the questions. A complete response would require delving into records (if they are available) from when these analyses were done 12-13 years ago.

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Wednesday, August 20, 2014 2:07 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID); Destefano, Frank (CDC/OID/NCEZID)
Subject: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)
Importance: High

Hi, Coleen. My name is Angela Fisher, and I work on vaccine safety communications with Abbigail Tumpey. Dr. Frieden's office has asked for an FAQ document on the Brian Hooker/MMR/Autism situation **by EOD today**. Attached please find the questions that we've compiled based upon direct feedback from the *London Sunday Times* reporter and from the scientific allegations made in the press release. **We need for you to please provide us with the answers**, and we'll edit/enhance them from a communications perspective. Additionally, we are pulling general messages that will be placed at the top of the document. Please don't hesitate to let me know if you have any questions. Thank you.

Best,

-Angela

Angela H. Fisher
Health Communications Specialist / Chenega Contractor
Division of Healthcare Quality Promotion (DHQP)
Centers for Disease Control and Prevention
1600 Clifton, Bldg. 16, 2113; MS A-07
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Telework: Tuesdays and Fridays

Brian Hooker re: increased incidence of autism in African-American Boys (2004 DeStefano et all *Pediatrics* study)

Main Messages:

- **IN DEVELOPMENT**

FAQs:

Brian Hooker re: increased incidence of autism in African-American Boys (2004 DeStefano et all Pediatrics study)

1. Was there a mistake made in the 2003 paper? (yes or no, need straight-forward response) Do we stand by the research and conclusions drawn in the 2003 paper?

(b)(5)

2. Was a cohort of African American children omitted from the 2003 Peds paper, and if so, why?
    - Why were children who did not have a valid State of Georgia birth certificate excluded? Was there a scientific basis for excluding children born outside of the state of Georgia in the study results?

(b)(5)

    - Could reducing the sample size by excluding these children have obscured a link between the MMR vaccine and autism in African American boys?

(b)(5)

3. Why was there a difference in the data findings for this study? Why did Dr. Hooker's study say that African-American boys receiving their first MMR vaccine before 36 months of age are 3.4 times more likely to develop autism vs. after 36 months?

(b)(5)

- Is there any other research that shows (or does not show) a link between MMR and autism among these children?

(b)(5)

4. What is CDC doing to research any potential link between vaccines and autism?

(b)(5)

5. Did CDC knowingly skew scientific data to support government policies?

6. Before a study is published in a publication such as *Pediatrics*, what is the approval/review process? [Don't peers have to review and confirm the findings prior to publication?]

(b)(5)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 20 Aug 2014 21:56:20 +0000
To: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Subject: FW: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)
Attachments: Talking points_Brian Hooker_MMR_Autism_8_20_2014 ISO response_af_fxd.docx

FYI

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Cl: (b)(6)
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Wednesday, August 20, 2014 5:55 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: RE: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)

I've added a couple of things.
Thanks,
Frank

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Wednesday, August 20, 2014 5:40 PM

To: Destefano, Frank (CDC/OID/NCEZID); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: RE: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)

Thank you, Frank. I've added in some general messages and resources to your document. Please see attached here. We look forward to incorporating NCBDDD's feedback.

Best,

-Angela

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Wednesday, August 20, 2014 5:29 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: RE: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)

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Sent: Wednesday, August 20, 2014 2:07 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID); Destefano, Frank (CDC/OID/NCEZID)
Subject: URGENT REQUEST - FAQ input needed for FAQ for Dr. Frieden (Deadline: EOD today)
Importance: High

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Best,

-Angela

Angela H. Fisher
Health Communications Specialist / Chenega Contractor
Division of Healthcare Quality Promotion (DHQP)
Centers for Disease Control and Prevention
1600 Clifton, Bldg. 16, 2113; MS A-07

Atlanta, GA 30333
404-639-1665; c) (b)(6)
ahfisher@cdc.gov
Telework: Tuesdays and Fridays

(b)(5)

(b)(5)

(b)(5)

From: Chaney, Sascha (CDC/ONDIEH/NCEH)
Sent: Fri, 18 Sep 2015 08:51:33 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: Woodall Inquiry - Vaccine/Autism Link

FYI – For your awareness. Thanks!

From: Katsoyannis, Miranda (CDC/OD/CDCWO)
Sent: Friday, September 18, 2015 8:51 AM
To: Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Reott, Erica (CDC/ONDIEH/NCBDDD) <ipt1@cdc.gov>
Subject: RE: Woodall Inquiry - Vaccine/Autism Link

Thanks, that is what I thought. Stay tuned!

From: Chaney, Sascha (CDC/ONDIEH/NCEH)
Sent: Friday, September 18, 2015 8:50 AM
To: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>; Reott, Erica (CDC/ONDIEH/NCBDDD) <ipt1@cdc.gov>
Subject: RE: Woodall Inquiry - Vaccine/Autism Link

HI Randy – we are not funding this organization. Thanks!

From: Katsoyannis, Miranda (CDC/OD/CDCWO)
Sent: Friday, September 18, 2015 8:32 AM
To: Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Reott, Erica (CDC/ONDIEH/NCBDDD) <ipt1@cdc.gov>
Subject: FW: Woodall Inquiry - Vaccine/Autism Link

Greetings,

A staffer from Rep. Woodall is asking about International Bio Epidemiology Consultancy Services, Inc. (IBECS), a firm affiliated with Paul Thorsen. Specifically, he is asking on behalf of a constituent whether CDC is currently funding this organization.
Please advise and thanks,
Randy

From: Bigham, Jane E. (CDC/OD/CDCWO)
Sent: Thursday, September 17, 2015 5:14 PM
To: Katsoyannis, Miranda (CDC/OD/CDCWO) <mtk7@cdc.gov>; Brand, Anstice M. (CDC/OD/CDCWO) <atb6@cdc.gov>
Subject: Woodall Inquiry - Vaccine/Autism Link

Hi Randy,

I received the attached voicemail and follow up email (second attachment) from Nick Scoufaras in Woodall's office. Anstice did a little digging on the biotech firm that he references and there is an autism/vaccine link. I have not responded to Nick yet. Happy to respond and CC you/re-direct him or if you want to reach out directly, that works too of course!

Regards,
Jane

From: Microsoft Outlook **On Behalf Of** 2022450600
Sent: Thursday, September 17, 2015 9:33 AM
To: Bigham, Jane E. (CDC/OD/CDCWO) <vsy0@cdc.gov>
Subject: Voice Mail from 2022450600 (30 seconds)

Voice Mail Preview:

Hi Bigham this is nick with you also congressman were all I have a question about.

Biotech firm -- in George other than that it's receiving a fun so from your PDC so if you could give me a call back my phone number here is 2:02 -- 225

4272 again my name is nick thanks.

Created by Microsoft Speech Technology. Learn More...

You received a voice mail from 2022450600

Caller-Id:	2022450600

Sent: Thu, 16 May 2019 21:37:54 +0000
To: Joyner, Phil H. (CDC/OCOO/OSSAM)
Subject: FW: Your daughter wants you to see this

Hi Phil: forwarding this on to you. I find msg's like this personally very disturbing. I'm not sure what can be done about this, but anything that bring my children into this is a tipping point for me. I haven't opened the link, but just the subject line is just too much.

Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

-----Original Message-----
From: J [mailto:connecthealth@yahoo.com]
Sent: Tuesday, January 26, 2016 4:35 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: Your daughter wants you to see this

Hi, this may be interesting you: Truth in Media: CDC, Vaccines and Autism! This is the link:
http://truthinmedia.com/cdc-vaccines-autism-coverup/

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Thu, 6 Nov 2014 19:44:49 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: MMR vaccine and autism data set

I just spoke with Andy and no one has request the data.

Marshalyn Yeargin-Allsopp, MD
Medical Epidemiologist, DD Branch Chief
CDC, National Center on Birth Defects and Developmental Disabilities
MS E-86, 1600 Clifton Road, Atlanta, GA 30333
404-498-3842 Phone
404-498-3550 Fax

Delivery: 1825 Century Blvd NE, 3rd Floor, Atlanta GA 30345

To learn more about CDC's work in developmental disabilities, go to www.cdc.gov/ncbddd

From: MMWR (CDC)
Sent: Thu, 26 Mar 2015 13:04:53 -0400
To: CDC All - CDC & ATSDR and non-CDC & non-ATSDR
Subject: MMWR Vol. 64 / No. 11

Centers for Disease Control and Prevention
MMWR
Morbidity and Mortality Weekly Report

***MMWR* Weekly**
Vol. 64, No. 11
March 27, 2015

PDF of this issue

In this Issue

Adults with COPD who exercise and don't smoke are less likely to report activity limitations.

Brendan R. Jackson, MD, Shahed Iqbal, PhD, Barbara Mahon, MD.
MMWR Morb Mortal Wkly Rep 2015;64:305-8

Announcement: Autism Awareness Month and World Autism Day — April 2015
MMWR Morb Mortal Wkly Rep 2015;64:309

QuickStats: Colorectal Cancer Death Rates, by Sex — National Vital Statistics System, United States, 1999–2013
Betzaida Tejada-Vera, MS.
MMWR Morb Mortal Wkly Rep 2015;64:310

Notifiable Diseases and Mortality Tables
Link to PDF for Notifiable Diseases and Mortality Tables
Link to additional formats for Notifiable Diseases and Mortality Tables

---

***MMWR* Masthead**

Department of Health and Human Services
Centers for Disease Control and Prevention

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 23 Oct 2014 14:28:12 +0000
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: Quick question

Hi Andy: I have a quick question on the MMR-autism public use data file. Could you stop by when you have a minute? thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Berger, Sherri (CDC/OCOO/OD)
Sent: Wed, 21 Oct 2015 12:31:07 -0400
Subject: Rally on Clifton Road scheduled for October 23

This message is being sent to CIO directors, deputies and management officers –

We have learned that members of the public concerned about vaccines and autism are planning to gather in front of CDC Roybal campus on Friday, October 23. What is expected to be a peaceful demonstration should begin sometime in the morning, and media may be present.

Please keep the following in mind:

- There may be traffic congestion, please be cautious entering and leaving the campus.
- Individuals have the right to freedom of expression.
- The safety of staff, demonstrators, and neighbors comes first.
- Our individual actions reflect on all of us at CDC.

CDC Security is aware of the planned demonstration and will take appropriate safety precautions.

If you have security related questions before or during the demonstration, please contact OSSAM at ossam@cdc.gov. If you have any concerns or need to report an incident, call the Security Operations Center at 404.639.2888.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Wed, 10 Sep 2014 08:49:18 -0400
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Thomas, LaSundra (CDC/ONDIEH/NCBDDD) (CTR); Warren, Giselle Letitia (CDC/ONDIEH/NCBDDD) (CTR); Rice, Catherine (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Weber, Mary-Kate (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Spencer, Laura (CDC/OCOO/OCIO); Wright, Victoria (CDC/ONDIEH/NCBDDD)
Cc: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); William Thompson
Subject: RE: 2010 FOIA Cases --- Brian Hooker FOIAs regarding Diana Schendel & Paul Thorsen --- elephants in the room yesterday
Attachments: FW: I would like to ask that these e-mails be included in my file with the (b)(6) FOIAs

All,

I think the big elephant in the room yesterday was the fact that I put out a press release on August 27 where I say that I have been talking with Brian Hooker for the last 10 months and then the next day, the FOIA office decides to retrospectively ask me to search for documents regarding Diana Schendel and Paul Thorsen from FOIAs that are 4 years old. (see my press release below).

http://www.morganverkamp.com/august-27-2014-press-release-statement-of-william-w-thompson-ph-d-regarding-the-2004-article-examining-the-possibility-of-a-relationship-between-mmr-vaccine-and-autism/

I am happy to do the FOIA searches but I will tell you all up front what most of you already know. And I know this from reliable source inside and outside NCBDDD.

(b)(6)

So, to get these FOIA requests regarding Brian Hooker the day after I put out a press release that mentions my discussions with Brian Hooker seems odd.

In addition, I think everyone should know that (b)(6) (b)(6) (see attached). (b)(6) (b)(6)

"I presented a whole lot of Dianna Schendel's study results with Dr. Thorsen to a whole lot of people inside the CDC. If what I am hearing outside our center is true, then it seems like there are conflicts of interest that have not been shared with people in the scientific community. I am tired of this …."

Last but not least for this e-mail, when (b)(6) sends e-mails searching for information regarding (b)(6) that could damage his reputation under the heading FOIA, it's scary. It was scary for me and it was scary for (b)(6)

Anyways, if you read my press release, you will understand that families with children with autism are looking for transparency from the CDC.

Thanks,

Bill

-----Original Appointment-----
From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 28, 2014 2:48 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Thomas, LaSundra (CDC/ONDIEH/NCBDDD) (CTR); Warren, Giselle Letitia (CDC/ONDIEH/NCBDDD) (CTR); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Rice, Catherine (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Weber, Mary-Kate (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Spencer, Laura (CDC/OCOO/OCIO); Wright, Victoria (CDC/ONDIEH/NCBDDD)
Subject: 2010 FOIA Cases
When: Tuesday, September 09, 2014 10:00 AM-11:00 AM (UTC-05:00) Eastern Time (US & Canada).
Where: OD Conference

Hi All,

We have 5 FOIAs from 2010 that we are being asked to collect documents for. I already have files from Phyllis for 10-00556 from Marshalyn and Laura.

Originally we responded that we were providing all the same documents for all the requests however the FOIA office has instructed that we need to do individual searches for each one. As these are from 2010 we are under somewhat of a time crunch on these and are hoping to have

them done by the end of the year. So we need to conduct new searches for each of these separately. I have attached all the requests here.

(b)(5)

<< File: Incoming Request.pdf >> << File: Incoming request.pdf >> << File: 10-00697 Incoming Request.pdf >> << File: 10-00579 Incoming Request.pdf >> << File: 10-00696 Hooker.pdf >> << File: Search Form CURRENT-2013.docx >> << File: Search Description Form.pdf >>
Prior to the meeting please take the time to review each of these requests and brainstorm your questions. Please let me know if you have any questions before the meeting.

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Mon, 18 Nov 2013 15:02:09 -0500
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

We can discuss this as part of the meeting tomorrow morning but I do not anticipate recusing myself or my staff from this review.

Sal.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 12:28 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

All,

Given that the current plan was for a panel of NCBDDD staff to review all my documents and given they may directly impact our center director, I am going to request that all of you recuse yourself from viewing any of these documents. If this sounds reasonable, then can someone put me in touch with a staff member from CDC OGC? I think that would help alleviate some my concerns and anxiety regarding confidentiality.

Thanks,

Bill

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 10:02 AM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Elizabeth,

As I said in previous e-mails, I have to make decisions regarding what are private confidential notes and given that the notes reference our center director, I am not comfortable having someone in our center making those copies. So I would like to do that off site.

Does that make sense to you? And would you please ask CDC OD FOIA office if I can provide receipts to be reimbursed for copying?

Thanks,

Bill

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 9:58 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

I will follow up on this end. Can you also ask your branch if they have funding for this? I am a little confused as to why you are not copying the notes here where it is free?

Thanks!

Elizabeth A. Belser-Vega

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 9:56 AM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Elizabeth,

Can you also ask this of the CDC OD FOIA office since I have a whole bunch of separate FOIAs that I have to respond to too?

Thanks,

Bill

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 9:26 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Hi Bill,

Sal is out sick so that is why we rescheduled our meeting. I am sure he will respond to this question when he returns next week.

Thanks,

Elizabeth A. Belser-Vega

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 14, 2013 9:25 AM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Sal,

I see that you had to cancel our meeting this morning. I just spent $50 to copy 1.5 years worth of thimerosal & autism related notes that I have. So if we estimate that I have 13 years worth of notes since I started working on these studies in 2000 and we assume an estimate of $50 per 1.5 years then I will need approximately $433 to copy all of my notes. Is it possible for me to get a CDC credit card to cover the cost of copying all of these notes? Or could I just bring in a receipt from Kinkos for all the required copying.

Thanks,

Bill

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Friday, November 08, 2013 8:30 AM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Sal,

I have a couple of questions to ask you before our meeting next week since you are relying on CDC OGC staff for answers to my questions. Given that it looks like you will be interpreting CDC OGC advice, I would like to get advice from several other sources regarding what documents I need to share.

1. Am I allowed to consult directly with the CDC OGC that provided you guidance?
2. Am I allowed to consult directly with HHS OGC?
3. Am I allowed to consult directly with Congressional staffers?

Thanks,

Bill

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:41 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

I do want you there. Sorry for any confusion

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:09 PM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Sal – You cc'd me so I wasn't sure whether you wanted me included in that meeting. If not, I will wait to hear back from you. Thanks, Bill

---

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:03 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: OGC Guidance

Let's set up some time next week to walk through the guidance OGC sent me on Bill's question.

Sal.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Mon, 18 Nov 2013 18:43:05 -0500
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Ghosh, Sudevi (CDC/OCOO/OGC); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Thanks for the clarification Sal. Given I had asked this question on November 8th and you didn't respond until today, November 18th, it seems like asking me to respond the Congressional request by the 22nd might be a little unreasonable.

Since you have decided to add both Cindy and Marshalyn to this e-mail, I have also added Laura to this e-mail since she is my direct supervisor.

Just for historical purposes, I think everyone should know how I have been involved in the Thimerosal and MMR autism studies over the last 13 years.

1. I was the project officer on the 2 most expensive thimerosal studies the CDC carried out. Over $10 million dollars was spent carrying these 2 studies out. The 2 studies took 10 years to complete. I also finished and published a reanalysis of these 2 studies in 2012. As I have told Marshalyn, I plan on doing no vaccine safety studies in the future.
2. Sal told me by e-mail that I need to share my study notes associated with all of these studies. I have not done that previously and I am not sure that anyone else has. If they have, no one has told me that they have actually done that.
3. Therefore, I have a whole lot of study notes to review that are interspersed with a whole lot of other information in them. They cannot not be easily searched for either the Congressional request or the FOIAs.
4. Interspersed throughout these notes is a lot of personal private information including information about being (b)(6) at the peak of the craziness in February 2004.
5. I have had to consult with a lawyer previously when there were questions about what needed to be shared and this was prior to me being hospitalized. In November 2003 I shared everything I had including analyses and results from several of these studies and I am assuming they were screened out of what was shared with the DOJ and Congress but I have never been told that was actually the case since no one communicates what's been shared.
6. In the last Congressional request this last spring, I shared everything again, and this time many of the e-mails were leaked to individuals outside congress which included e-mails I had written 2 days before being hospitalized. So clearly a whole new set of rules is being used for what is shared and what isn't shared and no information is being shared with those of us that it actually impacts. My assumption is that HIPAA rules were violated because I don't think anyone actually knew what they were sharing. There was also a note added to the document that was shared that I would like to know who added it.
7. Last but not least, I presented a whole lot of Dianna Schendel's study results with Dr. Thorsen to a whole lot of people inside the CDC. If what I am hearing outside our center is

true, then it seems like there are conflicts of interest that have not been shared with people in the scientific community. I am tired of this shit.

Bill

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Monday, November 18, 2013 3:16 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Ghosh, Sudevi (CDC/OCOO/OGC); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Bill:

The Office of General Counsel at CDC is a branch of HHS/OGC so there is no real distinction between the two entities. Any program person can reach out to our OGC attorney-advisors on any issue. Sudevi Ghosh serves in this capacity for our Center. While there is no requirement to do so, many of the program requests to OGC are routed through this office for a response. In the case of FOIA, all requests should be routed through Kim Smith and this office for response.

Finally, as you probably know Executive Branch staff are generally not permitted to engage Congress directly. These interactions are generally managed by CDC/OD staff offices (CDC/W, FMO/L) or HHS (ASL). Any interactions we have on this or any other issue would be managed by one of these administrative offices. Further, in the event a Congressional staffer reaches out to you directly in any manner (phone, email, cell phone, correspondence), that staffer or the correspondence should be referred to my office (me or Kinzie Lee) immediately for a coordinated response through proper channels.

I hope this clarifies your questions,

Sal.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Friday, November 08, 2013 8:30 AM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Sal,

I have a couple of questions to ask you before our meeting next week since you are relying on CDC OGC staff for answers to my questions. Given that it looks like you will be interpreting CDC OGC advice, I would like to get advice from several other sources regarding what documents I need to share.

1. Am I allowed to consult directly with the CDC OGC that provided you guidance?
2. Am I allowed to consult directly with HHS OGC?

3. Am I allowed to consult directly with Congressional staffers?

Thanks,

Bill

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:41 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

I do want you there. Sorry for any confusion

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:09 PM
To: Lucido, Sal (CDC/ONDIEH/NCBDDD); Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Lee, Kinzie (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: OGC Guidance

Sal – You cc'd me so I wasn't sure whether you wanted me included in that meeting. If not, I will wait to hear back from you. Thanks, Bill

---

From: Lucido, Sal (CDC/ONDIEH/NCBDDD)
Sent: Thursday, November 07, 2013 5:03 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Gibbs Shields, Julie I. (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD)
Subject: OGC Guidance

Let's set up some time next week to walk through the guidance OGC sent me on Bill's question.

Sal.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 16 Sep 2015 20:29:34 +0000
To: Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Subject: RE: AAP talk- Candice please see below -- Flu?

I think that is fine. thx

From: Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, September 16, 2015 3:46 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: AAP talk- Candice please see below -- Flu?

Hi Coleen,

Did Kathleen give us a deadline for sending this information? If not, would you like me to reach out to see if tomorrow would be ok?

Thanks,
Candice

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, September 16, 2015 2:17 PM
To: Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Peacock, Georgina (CDC/ONDIEH/NCBDDD)
Subject: RE: AAP talk- Candice please see below -- Flu?

Candice,

Just got this to Joe's group now that we have seen the abstract. Would noon tomorrow be OK?

Thanks,

Cindy

From: Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, September 15, 2015 4:46 PM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Peacock, Georgina (CDC/ONDIEH/NCBDDD) <ghn3@cdc.gov>
Cc: DHDD OD Requests (CDC) <dhddodrequests@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>
Subject: RE: AAP talk- Candice please see below -- Flu?

Hi Cindy and Georgina,

Just checking in about this… have you decided which topics/bullet points we should send forward? Please let me know what I can do to help.

Candice

From: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 11:30 AM
To: Peacock, Georgina (CDC/ONDIEH/NCBDDD)
Cc: Hoffmann, Candice (CDC/ONDIEH/NCBDDD); DHDD OD Requests (CDC); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: RE: AAP talk- Candice please see below -- Flu?

Hi Georgina,

Flu is probably not global enough but what about the great partnership we have had with AAP around getting children vaccinated and showing that children with neuro disorders were at particular risk. I've been meaning to check with you about the letter that has been going out to providers each year as well as how we have featured the website in years past.

What about global prevention of NTDs, efforts to fortify? Also, I learned that CRS has been eliminated in the America's by vaccination programs (not our stuff but should be of interest to Peds).

Cindy

From: Peacock, Georgina (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 8:20 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>
Cc: Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Hoffmann, Candice (CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>; DHDD OD Requests (CDC) <dhddodrequests@cdc.gov>
Subject: Re: AAP talk- Candice please see below

Yes, I was thinking in addition to ADHD.

Sent from my BlackBerry 10 smartphone on the Verizon Wireless 4G LTE network.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 8:14 AM
To: Peacock, Georgina (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Cc: Moore, Cynthia (CDC/ONDIEH/NCBDDD); Hoffmann, Candice (CDC/ONDIEH/NCBDDD); DHDD OD Requests (CDC)
Subject: RE: AAP talk- Candice please see below

Please include the ADHD work too. We need to reinforce this with TF. thx

---

From: Peacock, Georgina (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 8:14 AM
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Cc: Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Hoffmann, Candice

(CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>; DHDD OD Requests (CDC) <dhddodrequests@cdc.gov>
Subject: Re: AAP talk- Candice please see below

Might be good to send a point about peds preparedness . We will get you a few points.
Georgina

Sent from my BlackBerry 10 smartphone on the Verizon Wireless 4G LTE network.

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 8:04 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Peacock, Georgina (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Subject: RE: AAP talk- Candice please see below

Sounds great, and copying Candice who will reach out to them, b

---

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 8:02 AM
To: Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>
Cc: Peacock, Georgina (CDC/ONDIEH/NCBDDD) <ghn3@cdc.gov>; Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>
Subject: RE: AAP talk

Please do. How about I let Kathleen know we will get her some talking points by midweek. I am including Georgina and Cindy on this email since they might have some thoughts of the 2-3 key points we would like to those attending the AAP conference hear from TF in reference to our Center.

Thanks

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Monday, September 14, 2015 7:50 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: AAP talk

Hey there,
I can have Candice coordinate this, sound good?

b

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Friday, September 11, 2015 6:38 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>
Subject: RE: AAP talk

Hi Coleen,
I checked in with Kathryn Foti about Dr Frieden's AAP presentation in case we could get some points about ADHD and autism in. She said the focus is primarily global but if we send her some material she'll see if she can get it in. I'm happy to do whatever I can.
Kathleen

Sent with Good (www.good.com)

-----Original Message-----
From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, September 11, 2015 04:40 PM Eastern Standard Time
To: Ethier, Kathleen (CDC/OD/PPEO)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: AAP talk

Kathleen: You mentioned that you are helping with Tom's upcoming talk at the AAP conference. Can we send along some talking points for consideration? Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Mon, 18 Jul 2016 09:33:09 -0400
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Thanks. I will send this link to Dr. Hooker.

Frank DeStefano, MD, MPH

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Monday, July 18, 2016 8:34 AM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Hi Frank –

The new link to request the MMR/autism data set is http://www.cdc.gov/ncbddd/developmentaldisabilities/maddsp-data-sets.html.

Andrew R. Autry, PhD
IT Project Manager
4770 Buford Highway MS E-86
Atlanta GA 30341
404-498-3876 (office)
I telework on Wednesday and Friday

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 3:15 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Hi Frank –

The requests for public use data sets usually come in via NCBDDDData@cdc.gov. The link to the procedures is http://www.cdc.gov/ncbddd/dd/data.htm, but the link is broken. It points to a page saying the instructions are no longer found. I'll check with our Communications people ASAP.

Andrew R. Autry, PhD
IT Project Manager
4770 Buford Highway MS E-86
Atlanta GA 30341
404-498-3876 (office)
I telework on Wednesday and Friday

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 2:28 PM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD) <aea6@cdc.gov>
Cc: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Hi Andy: Could you please f/u with Frank's question? I can't remember the process for requesting the MMR-autism data, but I do know the request comes through you. Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Friday, July 15, 2016 2:23 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Coleen,
I am sorry, but I have forgotten who the keeper of the public use data set is. Can you get this request to the right person? If you'd prefer, you could just let me know who handles the request and I can provide the information to Dr. Hooker.
Thanks,
Frank

Frank DeStefano, MD, MPH

From: Brian Hooker [mailto:(b)(6)@simpsonu.edu]
Sent: Friday, July 15, 2016 1:57 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Wharton, Melinda (CDC/OID/NCIRD) <mew2@cdc.gov>; CDC ISO Public Use Data Set <publicdataset@cdc.gov>
Subject: Access to data set for Destefano et al. 2004 MMR autism public use data set

Dear Dr. Destefano

I was granted access to the CDC's public use data set for the Destefano et al. 2004 MMR autism study in early 2014, as per directions on the CDC's website. Since then, I have been in contact with several other researchers who have not been successful in accessing such data.

Could you please let me know if those data are still available and how they may be accessed? I have had several requests to share the data directly which is in violation of the agreement I signed and I won't share the data regardless.

Please clarify this for me as soon as possible so I may get back to the researchers wanting the data.

Regards,

Brian

--
Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)

(b)(6) (cell)
(b)(6) @simpsonu.edu

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Fri, 15 Jul 2016 15:58:56 -0400
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Andy,
It's good to hear from you and thanks for the follow-up.
Frank

Frank DeStefano, MD, MPH

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 3:32 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

I asked Ursula to have the web team fix the broken link. They are working on it.

Andrew R. Autry, PhD
IT Project Manager
4770 Buford Highway MS E-86
Atlanta GA 30341
404-498-3876 (office)
I telework on Wednesday and Friday

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 3:15 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Hi Frank –

The requests for public use data sets usually come in via NCBDDDData@cdc.gov. The link to the procedures is http://www.cdc.gov/ncbddd/dd/data.htm, but the link is broken. It points to a page saying the instructions are no longer found. I'll check with our Communications people ASAP.

Andrew R. Autry, PhD
IT Project Manager
4770 Buford Highway MS E-86
Atlanta GA 30341
404-498-3876 (office)
I telework on Wednesday and Friday

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 2:28 PM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD) <aea6@cdc.gov>
Cc: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Hi Andy: Could you please f/u with Frank's question? I can't remember the process for requesting the MMR-autism data, but I do know the request comes through you. Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy.
Atlanta, GA 30341

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Friday, July 15, 2016 2:23 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Subject: FW: Access to data set for Destefano et al. 2004 MMR autism public use data set

Coleen,
I am sorry, but I have forgotten who the keeper of the public use data set is. Can you get this request to the right person? If you'd prefer, you could just let me know who handles the request and I can provide the information to Dr. Hooker.
Thanks,
Frank

Frank DeStefano, MD, MPH

From: Brian Hooker [mailto:(b)(6)@simpsonu.edu]
Sent: Friday, July 15, 2016 1:57 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Cc: Wharton, Melinda (CDC/OID/NCIRD) <mew2@cdc.gov>; CDC ISO Public Use Data Set <publicdataset@cdc.gov>
Subject: Access to data set for Destefano et al. 2004 MMR autism public use data set

Dear Dr. Destefano

I was granted access to the CDC's public use data set for the Destefano et al. 2004 MMR autism study in early 2014, as per directions on the CDC's website. Since then, I have been in contact with several other researchers who have not been successful in accessing such data.

Could you please let me know if those data are still available and how they may be accessed? I have had several requests to share the data directly which is in violation of the agreement I signed and I won't share the data regardless.

Please clarify this for me as soon as possible so I may get back to the researchers wanting the data.

Regards,

Brian

--
Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)
(b)(6) (cell)
(b)(6)@simpsonu.edu

From: Harben, Kathy (CDC/OD/OADC)
Sent: Fri, 15 Jul 2016 15:12:50 -0400
To: Gonzalez, Belsie (CDC/OD/OADC); Destefano, Frank (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Hoskins, Sharon (K.D.) (CDC/OD/OADC); DeNoon, Daniel (CDC/OD/OADC) (CTR); Bryant, LaKia R. (CDC/OD/OADC); Flynn, Paige (CDC/OD/OCS); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD); Atkins, Bret (CDC/ONDIEH/NCBDDD)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Haynes, Benjamin (CDC/OD/OADC); Bonds, Michelle E. (CDC/OD/OADC); Galatas, Kate (CDC/OD/OADC); Reynolds, Barbara S. (CDC/OD/OADC)
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set
Importance: High

All, KD is on leave until Monday, June 18. We are currently working on a FOIA that may be related to this request. I'm not familiar with the request in 2014 but suggest we hear from Laura, Bret, and people working on the FOIA before we respond to this request or before sharing any data. Please confirm receipt of this message.

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Friday, July 15, 2016 2:59 PM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD) <aea6@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Cc: Weintraub, Eric (CDC/OID/NCEZID) <eiw8@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Evidently, Eric has also received the current message and a couple of previous requests for the data. He forwarded them to Belsie, who had been designated as the contact for the public use data requests. Please let us know if procedures have changed.
Thanks,
Frank

Frank DeStefano, MD, MPH

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Friday, July 15, 2016 2:36 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Cc: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

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Andrew R. Autry, PhD
IT Project Manager
4770 Buford Highway MS E-86
Atlanta GA 30341
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Cc: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>
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Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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Ph: 404-498-3800
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Subject: Access to data set for Destefano et al. 2004 MMR autism public use data set

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Regards,

Brian

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Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)
(b)(6) (cell)
(b)(6) @simpsonu.edu

From: Weintraub, Eric (CDC/OID/NCEZID)
Sent: Fri, 15 Jul 2016 15:18:48 -0400
To: Gonzalez, Belsie (CDC/OD/OADC); Destefano, Frank (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Hoskins, Sharon (K.D.) (CDC/OD/OADC)
Cc: Harben, Kathy (CDC/OD/OADC); Haynes, Benjamin (CDC/OD/OADC)
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Below are the 2 request we received at publicdataset@cdc.gov that I forwarded to Belsie.

1) Received on July 4th

Dear Friends

I have another research colleague that would like to access the public use data set for the Destefano et al. 2004 study. Could you please let me know if that data set is still accessible? Thank you.

Brian Hooker

--
Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)
(b)(6) (cell)
(b)(6) @simpsonu.edu

2) Received on July 7th

Dear Colleagues:

I would like to request the public use data set for the Destefano et al. 2004 CDC study on the MMR and autism. Could you please send me the application form and necessary information in order to obtain the data set?

Best Regards,

W. Bryan Smith
Morgan & Morgan

One Commerce Square, Suite 2600
Memphis, Tennessee 38103
Direct: (901) 333-1813
Fax: (901) 524-1771
(b)(6) @forthepeople.com

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Friday, July 15, 2016 3:03 PM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Autry, Andrew (CDC/ONDIEH/NCBDDD) <aea6@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Hoskins, Sharon (K.D.) (CDC/OD/OADC) <sdh4@cdc.gov>
Cc: Weintraub, Eric (CDC/OID/NCEZID) <eiw8@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>; Haynes, Benjamin (CDC/OD/OADC) <fxq2@cdc.gov>
Subject: RE: Access to data set for Destefano et al. 2004 MMR autism public use data set

Greetings,

I am in Puerto Rico working on the Zika Response, KD Hoskins is covering this topic.

Thank you,

Belsie

Belsie González, MPH
Senior Public Affairs Specialist I Centers for Disease Control and Prevention I
bgonzalez2@cdc.gov I 404-370-2027 I

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Friday, July 15, 2016 2:59 PM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD) <aea6@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>
Cc: Weintraub, Eric (CDC/OID/NCEZID) <eiw8@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
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Regards,

Brian

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Associate Professor of Biology
Chair, Division of Sciences and Mathematics
Simpson University
(530) 226-4734 (desk)

(b)(6) (cell)
(b)(6) @simpsonu.edu

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Tue, 14 Oct 2014 17:52:41 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

Coleen, your description for data requests related the MMR-Autism 2004 Pediatrics paper is correct. We have provided the same link we included on the CDC statement: http://www.cdc.gov/ncbddd/developmentaldisabilities/maddsp-data-sets.html

Regards,

Belsie

Belsie González, MPH
Senior Public Affairs Specialist

News Media Branch | Division of Public Affairs
Office of the Associate Director for Communication
Centers for Disease Control and Prevention (CDC)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, October 14, 2014 5:47 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

Hi Frank: Belsie Gonzales is helping to triage requests for the MMR-Autism public use data set. We have had in place since 2004 a protocol for request for the data. Since the data file provided to Dr. Hooker earlier this year was obtained through an ISO process, we would suggest that the new request follow the NCBDDD protocol. We understand that a few other individuals have inquired about access and we have guided them to this protocol for their request as well. Belsie will follow up with Dr. Hooker (Belsie, pls correct me if there is another way you are managing replies to such requests.)

Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Tuesday, October 14, 2014 8:59 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Weintraub, Eric (CDC/OID/NCEZID)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

Hi Coleen,
Can you let us know how to respond or if you would like this referred to someone in your center?
Thanks,
Frank

From: Weintraub, Eric (CDC/OID/NCEZID)
Sent: Tuesday, October 14, 2014 8:26 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: FW: Access to public use data for Destefano et al. 2004 paper

Frank, who should I send this to over in Birth Defects. I want to make sure the proper procedures are followed to extend the DUA to the University Folks. Could be a simple as just having them complete the DUA, but want to make sure.
(I'll respond to him through our anonymous email address)
Thanks

eric

From: Brian Hooker [mailto:(b)(6) @simpsonu.edu]
Sent: Monday, October 13, 2014 1:30 PM
To: CDC ISO Public Use Data Set
Subject: Access to public use data for Destefano et al. 2004 paper

Dear Colleagues

I received access to the public use dataset for the Destefano et al. 2004 paper and am now working with colleagues from University of British Columbia Statistical Consulting and Research Laboratory. Could you please let me know what I need to do to extend access to the Destefano data to this group? Thank you very much!

Brian

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Simpson University
(530) 226-4734 (desk)
(b)(6) (cell)
(b)(6) @simpsonu.edu

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Tue, 14 Oct 2014 19:06:34 -0400
To: Weintraub, Eric (CDC/OID/NCEZID); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

I will coordinate a response to him.

Regards,

Belsie

Belsie González, MPH
Senior Public Affairs Specialist

News Media Branch | Division of Public Affairs
Office of the Associate Director for Communication
Centers for Disease Control and Prevention (CDC)

From: Weintraub, Eric (CDC/OID/NCEZID)
Sent: Tuesday, October 14, 2014 7:05 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID)
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

So in Summary, you will be responding to Brian Hookers request below?

Thanks, eric

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, October 14, 2014 5:47 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

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National Center on Birth Defects and Developmental Disabilities
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From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 15 Oct 2014 14:29:04 +0000
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

Belsie is the point person. thx

Coleen A. Boyle, PhD, MS hyg
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Atlanta, GA 30333

Ph: 404-498-3800
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cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Wednesday, October 15, 2014 10:09 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Access to public use data for Destefano et al. 2004 paper

Thanks for the clarification. We will send any future requests for the MMR-Autism public use data set to Belsie unless there is someone else that you would like to handle the requests.
Frank

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, October 14, 2014 5:47 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Weintraub, Eric (CDC/OID/NCEZID); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Gonzalez, Belsie (CDC/OD/OADC)
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Subject: Access to public use data for Destefano et al. 2004 paper

Dear Colleagues

I received access to the public use dataset for the Destefano et al. 2004 paper and am now working with colleagues from University of British Columbia Statistical Consulting and Research Laboratory. Could you please let me know what I need to do to extend access to the Destefano data to this group? Thank you very much!

Brian

--
Brian S. Hooker, Ph.D., P.E.
Associate Professor of Biology
Simpson University
(530) 226-4734 (desk)
(b)(6) (cell)
(b)(6) @simpsonu.edu

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 26 Aug 2014 17:41:25 +0000
To: McCabe, Edward
Cc: Gore, Lorraine
Subject: RE: Anti-Vax Article

Hi Ed: Please see the following link to CDC's response. If you have further questions, please feel free to call me. Thanks, Coleen

http://www.cdc.gov/vaccinesafety/Concerns/Autism/cdc2004pediatrics.html

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: McCabe, Edward [mailto:(b)(6)@marchofdimes.com]
Sent: Tuesday, August 26, 2014 12:04 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Gore, Lorraine
Subject: Anti-Vax Article

Coleen,

Our chapters are getting questions about the (b)(6) paper attached. He used African American males that your group excluded and I could see that leading to biased comparisons between the groups.

How are you responding? This will help us in our responses.

Thank you.

Ed

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thu, 21 Aug 2014 15:13:34 -0400
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: (b)(6)
Subject: RE: As a friend and a colleague

Well, it looks like the times don't work. We will not schedule a meeting for now and perhaps reconsider later.
Thanks,
Frank

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 21, 2014 12:55 PM
To: Destefano, Frank (CDC/OID/NCEZID); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: (b)(6)
Subject: RE: As a friend and a colleague

I can only do 2:00 – 3:00. Where would you like to meet?

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, August 21, 2014 12:31 PM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: (b)(6)
Subject: Re: As a friend and a colleague

I am available at those times.

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 21, 2014 12:16 PM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: (b)(6) (b)(6) Destefano, Frank (CDC/OID/NCEZID)
Subject: RE: As a friend and a colleague

Hi Bill,

I am available from 8-9:30 and 3-4.

Thanks!
Marshalyn

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 21, 2014 12:07 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)

Cc: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); (b)(6) Destefano, Frank (CDC/OID/NCEZID)
Subject: FW: As a friend and a colleague

Coleen & Marshalyn,

Frank thinks the four of us should get together to discuss the paper tomorrow. Can you suggest times you are available?

Thanks,

Bill

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, August 21, 2014 10:13 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: Re: As a friend and a colleague

I appreciate it. Thanks.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 21, 2014 10:08 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: RE: As a friend and a colleague

I will set it up. Thanks. bill

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Thursday, August 21, 2014 9:23 AM
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: Re: As a friend and a colleague

I think we should have a meeting of the coauthors, including you, me, ML, and Coleen to go over this issue. We should meet today or tomorrow. Would you like me to set it up?

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Thursday, August 21, 2014 06:02 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: As a friend and a colleague

I hope you will back me up when I say we failed to report statistically significant race effects in the MMR-Autism study. Thanks, Bill

William W. Thompson, PhD

Senior Scientist

National Center of Birth Defects and Developmental Disabilities

U.S. Centers for Disease Control & Prevention

1600 Clifton RD, NE

Atlanta, GA, 30333

Cell: (b)(6)

Phone: (404) 498-3845

From: cab3@cdc.gov
Sent: Wed, 23 Mar 2016 11:33:28 -0400
To: Alex Kemper, M.D.
Subject: Re: Autism and Vaccines

Alex: thanks, I hope all is well with you too. Regards, Coleen

Sent from my iPad

On Mar 23, 2016, at 10:45 AM, Alex Kemper, M.D. <(b)(6) @duke.edu> wrote:

Coleen,
Hope you are well.
I wanted to make sure that you and your CDC colleagues were aware of this movie coming out: http://vaxxedthemovie.com
Alex

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Fri, 27 Feb 2015 10:35:42 -0500
To: Ethier, Kathleen (CDC/OD/PPEO)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Autism MMR folder location.

You're welcome!

Andrew R. Autry, PhD
IT Project Manager
1600 Clifton Road, MS E-86
Atlanta GA 30333
404-498-3876 (office)
(b)(6) *(cell)*
I telework on Wednesday and Friday

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Friday, February 27, 2015 9:50 AM
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Autism MMR folder location.

Hi Andrew – Looks like everything is in working order. Thanks so much!

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 26, 2015 3:40 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Autism MMR folder location.

Hi Dr. Ethier –

My name is Andrew Autry and I work for Coleen Boyle in NCBDDD. I have created a folder containing all of the materials that were previously posted to the Sharepoint Site and I have given you and Coleen read/write access. The path to the folder is:

(b)(6)

Please try to access the share. If you have any problems, please call me directly. Thank you.

Andrew R. Autry, PhD
IT Project Manager
1600 Clifton Road, MS E-86
Atlanta GA 30333
404-498-3876 (office)
(b)(6) *(cell)*
I telework on Wednesday and Friday

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 26 Feb 2015 22:07:08 +0000
To: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: RE: Autism MMR folder location.

Thank you!

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Autry, Andrew (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 26, 2015 3:40 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Autism MMR folder location.

Hi Dr. Ethier –

My name is Andrew Autry and I work for Coleen Boyle in NCBDDD. I have created a folder containing all of the materials that were previously posted to the Sharepoint Site and I have given you and Coleen read/write access. The path to the folder is:

(b)(6)

Please try to access the share. If you have any problems, please call me directly. Thank you.

Andrew R. Autry, PhD
IT Project Manager
1600 Clifton Road, MS E-86
Atlanta GA 30333
404-498-3876 (office)
(b)(6) *(cell)*
I telework on Wednesday and Friday

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 7 Oct 2014 15:54:46 +0000
To: Ghosh, Sudevi (CDC/OCOO/OGC); Destefano, Frank (CDC/OID/NCEZID)
Cc: Brower, Melissa (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: BMJ request re William Thompson

(b)(5)

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ghosh, Sudevi (CDC/OCOO/OGC)
Sent: Tuesday, October 07, 2014 11:19 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Brower, Melissa (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: Re: BMJ request re William Thompson

(b)(5)

Thanks.

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Tuesday, October 07, 2014 11:16 AM Eastern Standard Time
To: Ghosh, Sudevi (CDC/OCOO/OGC)

Cc: Brower, Melissa (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Subject: RE: BMJ request re William Thompson

(b)(5)

From: Ghosh, Sudevi (CDC/OCOO/OGC)
Sent: Tuesday, October 07, 2014 11:13 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Cc: Brower, Melissa (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Subject: Re: BMJ request re William Thompson

(b)(5)

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Tuesday, October 07, 2014 10:56 AM Eastern Standard Time
To: Ghosh, Sudevi (CDC/OCOO/OGC)
Cc: Brower, Melissa (CDC/OID/NCEZID); Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Subject: FW: BMJ request re William Thompson

(b)(5)

Frank

From: Rebecca Coombes [mailto:(b)(6)@bmj.com]
Sent: Tuesday, October 07, 2014 9:08 AM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: Fwd: BMJ request re William Thompson

Dear Dr. DeStefano,

I contacted you on Friday with the media request below. Can you please confirm that you received this email? And if so, are you planning to respond? We were hoping to gather responses by yesterday but are willing to wait another 24 hours.

All best,

Rebecca Coombes
Magazine Editor
BMJ

BMJ, BMA House, Tavistock Square, London, WC1H 9JR
T: (b)(6)
E: (b)(6) @bmj.com
W: bmj.com/company
Twitter: @rebeccacoombes

---------- Forwarded message ----------
From: **Rebecca Coombes** <(b)(6) @bmj.com>
Date: 2 October 2014 16:50
Subject: BMJ request re William Thompson
To: fxd1@cdc.gov

Dear Dr. DeStefano,

We at *The BMJ* were interested in recent statements made by William Thompson concerning a paper you co-authored with him in 2004 on MMR and autism (Pediatrics 2004;113:259–266).

For reference, Dr. Thompson's statements are here:
http://www.morganverkamp.com/august-27-2014-press-release-statement-of-william-w-thompson-ph-d-regarding-the-2004-article-examining-the-possibility-of-a-relationship-between-mmr-vaccine-and-autism/

One of the statements Dr. Thompson makes is: "I regret that my coauthors and I omitted statistically significant information in our 2004 article published in the journal Pediatrics. The omitted data suggested that African American males who received the MMR vaccine before age 36 months were at increased risk for autism. Decisions were made regarding which findings to report after the data were collected, and I believe that the final study protocol was not followed."

I am trying to look into the matter to substantiate some of the claims. I have obtained a copy of the final study protocol from CDC.

Based on my reading of the materials, I have the following questions I was hoping you could answer:

1. Why did you not do an analysis by race for the full study population despite having the data and indicating this would be done in the final study protocol?

2. What would the results by race look like for the full study cohort?

3. Prior to publication of the manuscript, did you have results that "suggested that African American males who received the MMR vaccine before age 36 months were at increased risk for autism", as Dr. Thompson says?

May I have your response by 5:00 PM EST on Monday?

Thank you for your help.

Rebecca Coombes
Magazine Editor

BMJ, BMA House, Tavistock Square, London, WC1H 9JR
T: (b)(6)
E: (b)(6)
W: bmj.com/company

Twitter: @rebeccacoombes

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Fri, 5 Sep 2014 12:19:43 +0000
To: Ikeda, Robin (CDC/ONDIEH/OD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Subject: RE: Calls

That seems reasonable. thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

-----Original Message-----
From: Ikeda, Robin (CDC/ONDIEH/OD)
Sent: Friday, September 05, 2014 8:19 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Subject: Re: Calls

Perhaps we could suggest 1 call/week, beginning next week?

----- Original Message -----
From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, September 05, 2014 08:10 AM
To: Bonzo, Sandra E. (CDC/ONDIEH/OD); Ikeda, Robin (CDC/ONDIEH/OD)
Subject: RE: Calls

I would agree too -- I think it would be impt to discuss continued coordination, particularly between the different communication channels (as Frank and our grp handle additional requests) and with Sudevi. thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

-----Original Message-----
From: Bonzo, Sandra E. (CDC/ONDIEH/OD)
Sent: Friday, September 05, 2014 8:07 AM
To: Ikeda, Robin (CDC/ONDIEH/OD); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Re: Calls

I agree.

----- Original Message -----
From: Ikeda, Robin (CDC/ONDIEH/OD)
Sent: Friday, September 05, 2014 07:50 AM Eastern Standard Time
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Bonzo, Sandra E. (CDC/ONDIEH/OD)
Subject: Calls

I am thinking perhaps we don't need to continue standing vaccine/autism calls after today, but welcome your thoughts. Thx

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Mon, 3 Aug 2015 11:37:44 -0400
To: Skinner, Thomas W. (CDC/OD/OADC); Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC); Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Harben, Kathy (CDC/OD/OADC)
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Tom,

Please call me on my cell phone: (b)(6)

Thanks!
Marshalyn

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Monday, August 03, 2015 10:20 AM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>; Hoffmann, Candice (CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Thanks. I will call you all around noon. Please take a look at below statements before we talk. Thanks

"CDC is aware that employee Dr. William Thompson has raised concerns regarding an article he co-authored that was published in 2004 in Pediatrics. Consistent with CDC's existing policies and procedures, the agency, through its Office of the Associate Director for Science (ADS), and in coordination with the HHS Office of Research Integrity, is reviewing these concerns. The agency will provide further information once the review is completed."

http://www.cdc.gov/vaccinesafety/Concerns/Autism/cdc2004pediatrics.html

---

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Monday, August 03, 2015 9:48 AM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Skinner, Thomas W. (CDC/OD/OADC) <tws3@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

I am available except for 11-12.
Frank

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Monday, August 03, 2015 9:42 AM

To: Skinner, Thomas W. (CDC/OD/OADC); Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Harben, Kathy (CDC/OD/OADC)
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Hi Tom,
I am working from home but available any time today except 10-12.
Thanks!
Marshalyn

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Monday, August 03, 2015 9:36 AM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Would be good to speak on phone. Belsie is out this week. What time would be good to talk?

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Monday, August 03, 2015 9:14 AM
To: Skinner, Thomas W. (CDC/OD/OADC) <tws3@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>
Subject: FW: Comment on Thompson "garbage can" quote from Rep Posey?

How should we respond to this?
Thanks,
Frank

From: Emily Willingham [mailto:(b)(6) @gmail.com]
Sent: Sunday, August 02, 2015 6:48 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: Comment on Thompson "garbage can" quote from Rep Posey?

Dear Dr. DeStefano:

I'm sure you're aware of the "whistleblower" situation involving your co-author William Thompson. I am a contributor at Forbes who writes frequently about autism (and, by necessity, therefore, about autism and vaccines), and I was wondering if you could comment on this latest material that Congressman Bill Posey has attributed to Thompson:

At the bottom of Table 7 it also shows that for the non-birth certificate sample, the adjusted race effect statistical significance was huge. All the authors and I met and decided sometime between August and

September '02 not to report any race effects for the paper. Sometime soon after the meeting, we decided to exclude reporting any race effects, the co-authors scheduled a meeting to destroy documents related to the study. The remaining four co-authors all met and brought a big garbage can into the meeting room and reviewed and went through all the hard copy documents that we had thought we should discard and put them in a huge garbage can. However, because I assumed it was illegal and would violate both FOIA and DOJ requests, I kept hard copies of all documents in my office and I retained all associated computer files. I believe we intentionally withheld controversial findings from the final draft of the Pediatrics paper.

I infer that trashcan or no trashcan, many digital versions of these data, which were derived from existing databases, remained available for record-keeping. Would you be able to confirm that?

Thus far, this story has had zero balance regarding Thompson's statements or representations of his statements. I would, at the least, like to be able to provide an on-the-record version of what is described above ... even if it's attributed only to "one of the paper authors who was there." Any counterpoint and/or confirmation you can provide would be helpful.

Thank you for your time.

Best,
Emily Willingham

Emily Willingham, PhD
Science Writer and Editor

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Mon, 3 Aug 2015 11:39:41 -0400
To: Skinner, Thomas W. (CDC/OD/OADC); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC); Hoffmann, Candice (CDC/ONDIEH/NCBDDD)
Cc: Harben, Kathy (CDC/OD/OADC)
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Ok, thanks Tom. I will call the number below at noon.
Marshalyn

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Monday, August 03, 2015 11:06 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>; Hoffmann, Candice (CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>
Cc: Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

We can use this line at noon. Thanks

Call-In Number:
(b)(6)
Participant Passcode: (b)(6)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Monday, August 03, 2015 10:51 AM
To: Skinner, Thomas W. (CDC/OD/OADC) <tws3@cdc.gov>; Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>; Hoffmann, Candice (CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>
Cc: Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Noon works for me. Is there a call in # -- thx

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Monday, August 03, 2015 10:20 AM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>; Hoffmann, Candice (CDC/ONDIEH/NCBDDD) <hqx5@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Thanks. I will call you all around noon. Please take a look at below statements before we talk. Thanks

"CDC is aware that employee Dr. William Thompson has raised concerns regarding an article he co-authored that was published in 2004 in Pediatrics. Consistent with CDC's existing policies and procedures, the agency, through its Office of the Associate Director for Science (ADS), and in coordination with the HHS Office of Research Integrity, is reviewing these concerns. The agency will provide further information once the review is completed."

http://www.cdc.gov/vaccinesafety/Concerns/Autism/cdc2004pediatrics.html

---

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Monday, August 03, 2015 9:48 AM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Skinner, Thomas W. (CDC/OD/OADC) <tws3@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

I am available except for 11-12.
Frank

From: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Sent: Monday, August 03, 2015 9:42 AM
To: Skinner, Thomas W. (CDC/OD/OADC); Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Harben, Kathy (CDC/OD/OADC)
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Hi Tom,
I am working from home but available any time today except 10-12.
Thanks!
Marshalyn

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Monday, August 03, 2015 9:36 AM
To: Destefano, Frank (CDC/OID/NCEZID) <fxd1@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>; Harben, Kathy (CDC/OD/OADC) <kxh9@cdc.gov>
Subject: RE: Comment on Thompson "garbage can" quote from Rep Posey?

Would be good to speak on phone. Belsie is out this week. What time would be good to talk?

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Monday, August 03, 2015 9:14 AM
To: Skinner, Thomas W. (CDC/OD/OADC) <tws3@cdc.gov>; Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Yeargin-Allsopp, Marshalyn

(CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>
Subject: FW: Comment on Thompson "garbage can" quote from Rep Posey?

How should we respond to this?
Thanks,
Frank

From: Emily Willingham [mailto(b)(6) @gmail.com]
Sent: Sunday, August 02, 2015 6:48 PM
To: Destefano, Frank (CDC/OID/NCEZID)
Subject: Comment on Thompson "garbage can" quote from Rep Posey?

Dear Dr. DeStefano:

I'm sure you're aware of the "whistleblower" situation involving your co-author William Thompson. I am a contributor at Forbes who writes frequently about autism (and, by necessity, therefore, about autism and vaccines), and I was wondering if you could comment on this latest material that Congressman Bill Posey has attributed to Thompson:

At the bottom of Table 7 it also shows that for the non-birth certificate sample, the adjusted race effect statistical significance was huge. All the authors and I met and decided sometime between August and September '02 not to report any race effects for the paper. Sometime soon after the meeting, we decided to exclude reporting any race effects, the co-authors scheduled a meeting to destroy documents related to the study. The remaining four co-authors all met and brought a big garbage can into the meeting room and reviewed and went through all the hard copy documents that we had thought we should discard and put them in a huge garbage can. However, because I assumed it was illegal and would violate both FOIA and DOJ requests, I kept hard copies of all documents in my office and I retained all associated computer files. I believe we intentionally withheld controversial findings from the final draft of the Pediatrics paper.

I infer that trashcan or no trashcan, many digital versions of these data, which were derived from existing databases, remained available for record-keeping. Would you be able to confirm that?

Thus far, this story has had zero balance regarding Thompson's statements or representations of his statements. I would, at the least, like to be able to provide an on-the-record version of what is described above ... even if it's attributed only to "one of the paper authors who was there." Any counterpoint and/or confirmation you can provide would be helpful.

Thank you for your time.

Best,
Emily Willingham

Emily Willingham, PhD
Science Writer and Editor

From: cab3@cdc.gov
Sent: Mon, 3 Aug 2015 05:47:05 -0400
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD)
Cc: Moore, Cynthia (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: Re: Comment on Thompson "garbage can" quote from Rep Posey?

Hi Marshalyn: I believe there is a response that was developed. Could you send to Betsy who will send to the press office? They are handling inquires. Thanks, Coleen

Sent from my iPad

On Aug 2, 2015, at 7:20 PM, Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov> wrote:

Hi Cindy and Coleen,

Of course I have seen this online and I do not plan to comment. Is there an "official" response that I/we/CDC should provide?

Thanks!
Marshalyn

From: Emily Willingham [mailto:(b)(6)@gmail.com]
Sent: Sunday, August 02, 2015 6:58 PM
To: Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD) <mxy1@cdc.gov>
Subject: Comment on Thompson "garbage can" quote from Rep Posey?

Dear Dr. Yeargin-Allsopp:

I'm sure you're aware of the "whistleblower" situation involving your co-author William Thompson. I am an independent journalist and contributor at Forbes who writes frequently about autism (and, by necessity, therefore, about autism and vaccines), and I was wondering if you could comment on this latest material that Congressman Bill Posey has attributed to Thompson:

At the bottom of Table 7 it also shows that for the non-birth certificate sample, the adjusted race effect statistical significance was huge. All the authors and I met and decided sometime between August and September '02 not to report any race effects for the paper. Sometime soon after the meeting, we decided to exclude reporting any race effects, the co-authors scheduled a meeting to destroy documents related to the study. The remaining four co-authors all met and brought a big garbage can into the meeting room and reviewed and went through all the hard copy documents that we had thought we should discard and put them in a huge garbage can. However, because I assumed it was illegal and would violate both FOIA

and DOJ requests, I kept hard copies of all documents in my office and I retained all associated computer files. I believe we intentionally withheld controversial findings from the final draft of the Pediatrics paper.

I infer that trashcan or no trashcan, many digital versions of these data, which were derived from existing databases, remained available for record-keeping. Would you be able to confirm that?

Thus far, this story has had zero balance regarding Thompson's statements or representations of his statements. I would, at the least, like to be able to provide an on-the-record version of what is described above ... even if it's attributed only to "one of the paper authors who was there." Any counterpoint and/or confirmation you can provide would be helpful. I am reaching out to all of the authors on the paper with this query.

Thank you for your time.

Best,
Emily Willingham
(b)(6)

Emily Willingham, PhD
Science Writer and Editor

From: Moussakhani, Nisha (CDC/OID/NCHHSTP)
Sent: Mon, 16 Nov 2015 18:08:05 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD); Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD); Atkins, Bret (CDC/ONDIEH/NCBDDD); Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR); Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR); Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR); Chaney, Sascha (CDC/ONDIEH/NCEH); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Hunter, Karen (CDC/ONDIEH/NCBDDD); Chan, C. Leah (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD); Maenner, Matthew J. (CDC/ONDIEH/NCBDDD); Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13-16/2015
Attachments: NCHS_SocialMediaTracking_11 13-16 15.docx

Hi All,
Please find below and attached our updated compilation of media and social media coverage regarding the NCHS report: "*Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey*".

The top 3 additional stories highlighted in yellow below are what was pulled out of the news from late Friday through to today – similar coverage/messaging from the original compilation I sent on Friday where the headlines aren't so ideal but the majority of the reporting covers nicely our message and the differentiation between surveys/survey results and what they mean. The Tweet released from a local news channel in Oklahoma (see attached) was a little dramatic in my opinion, "New Official Number Of American Children With Autism Stirs Controversy #Oklahoma" but if you click on the Tweet and listen in on the reporter, he summarizes nicely.

Thanks again,
Nisha

Nisha Moussakhani, MPH
Press Officer/Health Communications Specialist
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
404-498-0846 (office)
(b)(6) (cell phone)
NMoussakhani@cdc.gov

NCHS Report on Autism Prevalence: Coverage Compilation
As of November 16th @ 6:00pm

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CDC COVERAGE

Autism rates nearly doubled in 2014: report
November 16, 2015
Newsmax Health

BY: Nick Tate
http://www.newsmax.com/Health/Health-News/autism-childrens-health-brain-health-brain-disorders/2015/11/16/id/702355/

Rates of autism among American children nearly doubled in 2014, according to a new analysis by the Centers for Disease Control and Prevention.

According to the new CDC survey of U.S. parents, the incidence of Autism Spectrum Disorder (ASD) in kid's ages 3 to 17 years jumped from 1.25 percent between 2011 and 2013 to 2.24 percent in 2014, the Wall Street Journal reports.

But researchers noted a small tweak in the way the 2014 survey was conducted may be responsible for the staggering new figures.

In 2014, the CDC changed the method of assessing prevalence of autism in children based on their parents' reports. In a 2011-2013 survey, parents had to answer three questions — whether their children were intellectually disabled, whether they noticed a developmental delay, and whether kids were previously diagnosed with Down syndrome, cell anemia, or other conditions.

A year later, CDC researchers asked directly whether the kids were diagnosed with ASD prior to the survey. About 10,000 parents take part in the CDC surveys every year.

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New government survey pegs autism prevalence at 1 in 45
November 13, 2015
Autism Speaks

https://www.autismspeaks.org/science/science-news/new-government-survey-pegs-autism-prevalence-1-45

A new government survey of parents suggests that 1 in 45 children, ages 3 through 17, have been diagnosed with autism spectrum disorder (ASD). This is notably higher than the official government estimate of 1 in 68 American children with autism, by the Centers for Disease Control and Prevention (CDC).

Because the new numbers come from a parent survey, they don't replace the CDC's 1-in-68 figure as the official estimate of autism prevalence in the United States.

However, the CDC has acknowledged that its estimate has significant limitations. It's based on an analysis of the medical and school records of 8-year-old children at monitoring sites across the country.

As such, it can miss children who are not receiving medical or special education services related to autism.

"The 1 in 45 estimate is not surprising and is likely a more accurate representation of autism prevalence in the United States," comments epidemiologist Michael Rosanoff, Autism Speaks director for public health research. "This means that 2 percent of children in the U.S. are living with autism. The earlier they have access to care, services and treatment, the more likely they are to progress."

The parent survey results released today are from the 2014 National Health Interview Survey. Conducted by the National Center for Health Statistics, it's the most in-depth survey of its kind in the United States. In all, more than 12,000 parents are interviewed on family health conditions. As part of the interview, one child in each family is randomly selected to be the subject of detailed questions on health and disabilities.

In part, the 2014 survey's high autism prevalence number reflects changes in the order and wording of the survey's questions, the authors say. They made these changes after noting that the questions on their 2011-2013 survey had likely confused parents and resulted in an underreporting of autism.

For exact wording and order of survey questions, see figure 1 below.

Indeed, the rewording and reordering of the questions produced a near doubling of reported autism diagnoses – from 1 in 80 in the 2011-2013 surveys to 1 in 45 in the 2014 survey.

The new numbers are more similar to those from another national parent survey – the 2013 National Survey of Children's Health – which found an autism prevalence of 1 in 50.

Pursuing more accurate numbers
In its effort to develop better methods for identifying autism and estimating prevalence, Autism Speaks has funded studies using active surveillance methods that go beyond parent reports and record reviews. In the first such study, in South Korea, researchers went into schools to screen children for autism. They found a prevalence of 1 in 38 – with many of the children having gone previously undiagnosed.

Autism Speaks and the CDC have since collaborated to support a study testing the same active screening methods in a U.S. community. The results are expected in 2016.

"We need to better understand not only who has autism," Rosanoff concludes, "but whether they are receiving the support they need and how we can ensure that they do receive it."

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U.S. survey shows higher rate of autism in children
November 13, 2015
Philly Voice

BY: David Beasley
http://www.phillyvoice.com/us-survey-shows-higher-rate-of-autism-in-children/

A new survey of parents suggests that as many as one out of every 45 U.S. children aged between 3 and 17 years have autism, a number that far exceeds official U.S. estimates of one in 68 children, U.S. researchers said on Friday.

The new parent survey results reflect a nearly doubling in autism rates over the last three years, but researchers at the U.S. Centers for Disease Control and Prevention, which released the data, say the shift is largely due to a change in the way the survey questions were worded.

The new numbers, which are based solely on a parent survey, do not replace CDC's official autism estimate of one in 68, which is based on more extensive research than parental surveys, agency researchers said.

For its survey, the CDC's National Center for Health Statistics contacted 43,283 parents using a new set of survey questions that included more specific diagnostic terms. Those changes may have caused more parents to say that their child had been diagnosed with autism or other developmental disabilities.

For example, the new survey included the names of specific diagnoses within the autism spectrum such as Asperger's and pervasive developmental disorder, categories that were "intended to help cue recall of past diagnoses," the CDC said.

CDC epidemiologist Benjamin Zablotsky told Reuters the new questions improved the accuracy of the survey, and did not reflect a surge in prevalence of autism in the United States.

"We obviously can't rule out entirely that there could be a true increase," Zablotsky said. "But that is something that would require really dramatic and rapid changes to the risk factors involved, and that seems unlikely."

In the survey, parents were asked whether they had ever been told by a doctor that their child had an intellectual disability, autism or another developmental delay. The prevalence of autism soared in the new survey, while parents reported far fewer cases of other developmental delays.

The combined total of autism cases and other developmental delays, however, was unchanged, suggesting that rewording the question helped parents answer more accurately, Zablotsky said,.

Michael Rosanoff of the advocacy group Autism Speaks said the one in 45 estimate is "not surprising" and is likely a more accurate representation of autism prevalence in the United States. The group has long suggested that U.S. officials have been underestimating the commonness of the condition.

Wendy Fournier, president of the National Autism Foundation and the mother of a 15-year-old child with the condition, said the results released on Friday offer "newer information that we feel better reflects the current prevalence of autism."

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Study finds more than 2% of children have autism
November 13, 2015
USA Today

BY: Liz Szabo
http://www.usatoday.com/story/news/2015/11/13/study-finds-more-than-2-children-have-autism/75673774/

A new survey has found a big jump in the number of children with autism, although researchers caution that the increase is likely due to the way that questions were asked. More than 2.2% of children ages 3 to 17 — about one in 45 — have autism, according to the Center for Disease Control and Prevention's National Health Interview Survey, conducted in 2014. The annual survey found autism rates of 1.25%, or one in 80 people, from 2011 to 2013.

People with autism — a complex condition of brain development — tend to have difficulty with social interaction and verbal and nonverbal communications and are prone to repetitive behaviors. While the CDC report describes autism as a development disability, some people with autism say they are simply different, rather than disabled.

The dramatic increase in autism rates in the latest survey suggests that parents used different labels to describe their children than in earlier years, said Katherine Walton, an assistant professor of psychiatry and psychology at Ohio State University, who wasn't involved in the new study. While the number of children diagnosed with autism went up, the number reporting children diagnosed with "other development delays" went down. Yet the overall number of parents who reported any developmental disability in their kids — about 5.75% — remained the same.

Parents may have changed the way they labeled their children because of changes made to the way that researchers interviewed them, said study coauthor Benjamin Zablotsky, a researcher at the CDC's National Center for Health Statistics. Different surveys have produced varying autism rates. The new survey results are similar to those of one released in 2013, which found 2% of children had autism. A study released in 2014 found the autism rate closer to 1.5%. Although studies have found rising rates of autism for two decades, there is no clear explanation why. It's possible that more children are developing the condition, Walton said. But she notes that the definition of autism is much broader today than it was decades ago. People also are more aware of autism, leading to increased testing of younger children. Multiple studies have ruled out vaccines as a cause of autism. Alison Singer, whose daughter has autism, said she's less interested in estimating the prevalence of autism than in securing support and services for her child. "As parents, we're not interested in '1 in 80' or '1 in 100.' We're interested in *our* one," said Singer, president of the Autism Science Foundation. "We're interested in getting access to services, making sure that children are in the appropriate classrooms and that adults with autism receive supported housing and employment, and that we're funding research to find the cause."

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Latest U.S. estimate suggests 1 in 45 children have autism
November 13, 2015
ABC News

BY: Mike Stobbe AP
http://abcnews.go.com/Health/wireStory/latest-us-estimate-suggests-45-children-autism-35171198

The government has a new estimate for autism — 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common. The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children. The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children. The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added. Estimates of how common autism is have been steadily increasing. In 2007, the CDC estimated 1 in 150 children had autism. For decades, autism meant kids with severe language, intellectual and social impairments and unusual, repetitious behaviors. But the definition has gradually expanded and now includes milder, related conditions. The cause or causes of autism are still not known. Experts say teachers and parents are increasingly likely to say a child with learning and behavior problems is autistic, so at least some of the apparent increase is due to different labeling. A third CDC survey issued two years ago — also based on parents' responses — came up with an estimate of 1 in 50 children with autism.

In the latest survey, some questions about autism were reworded to try to avoid confusion and get a more accurate figure, said lead author, Benjamin Zablotsky. "I think we'll continue to see the estimates getting closer" to each other, he said.

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Survey finds big increase in number of kids estimated to have autism
November 13, 2015
CNBC

BY: Maggie Fox
http://www.cnbc.com/2015/11/13/survey-finds-big-increase-in-number-of-kids-estimated-to-have-autism.html

A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism, and that parents are far more likely than in years past to seek a diagnosis for their kids. "One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study. "We feel we are asking the question in a better way than before," he said. It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often. Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism. "The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday. "In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote. "It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S." Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a large range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to 1 in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well. Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40 years ago. "These kids have always been there," Alderman told NBC News. "I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid." Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said. Now autism is something commonly talked about, and there's growing evidence that kids can be helped. "There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis." Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree. "Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or ... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services." Wiznitzer agrees that kids now diagnosed with autism would have had "another label" in the past. "We're just changing a child's diagnosis from, let's say, intellectual disability and mental retardation to autism spectrum disorder," he said. "Certainly one reason for the increase over time is that parents do come seeking the diagnosis," Shulman added. The findings fit in with other studies seeking to show whether autism is actually occurring more frequently, or simply being recognized and diagnosed more often. A team at Penn State University also found that children are being reclassified from something broad, like pervasive developmental disorder, to the more specific autism. And the NCHS found earlier this year that as many as 9 percent of children diagnosed with autism don't actually have it.

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1 in 45 American children has an autism spectrum disorder
November 13, 2015
Fox News Health

BY: Cari Nierenberg
http://www.foxnews.com/health/2015/11/13/1-in-45-american-children-has-autism-spectrum-disorder.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has

likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

***

Autism cases in U.S. jump to 1 in 45: Who gets the diagnosis, in 8 simple charts
November 13, 2015
The Washington Post

BY: Ariana Eunjung Cha
https://www.washingtonpost.com/news/to-your-health/wp/2015/11/13/autism-cases-in-u-s-rise-to-1-in-45-a-look-at-who-gets-the-diagnosis-in-8-simple-charts/
The number of autism cases in the United States appeared to jump dramatically in 2014 according to new estimates released Friday, but researchers said that changes in the format of the questionnaire likely affected the numbers.

The report from the Centers for Disease Control and Prevention and National Center for Health Statistics shows that the prevalence of autism in children ages 3 to 17 went up nearly 80 percent from 2011-2013 to 2014. Instead of 1 in 68 children having autism -- a number that has alarmed public health officials in recent years and strained state and school system resources -- researchers now estimate that the prevalence is now 1 in 45.

Lead author Benjamin Zablotsky, an epidemiologist at the NCHS, and his colleagues said that in previous years some parents of children diagnosed with autism spectrum disorder likely reported it as a developmental disability instead of or in addition to autism because it was listed first. The new questionnaire flips the two categories, which researchers said made the autism estimates more similar to ones from other sources.

As might be expected from this change, the prevalence of other developmental disabilities declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent in 2014.

The prevalence of intellectual disability did not significantly change and remains at 1.1 percent and the prevalence of any three of the conditions was constant across all surveys.

The high rates of autism among American children has been the source of much debate in recent years, with some experts attributing it to overdiagnosis and others expressing concern about possible environmental factors affecting children's brain development.

“It’s not the year to year numbers that concern us. It’s the decade to decade. The fact that we have 1 in 45 children with a very serious neurological condition is a catastrophe by any measure,” said Jill Escher, president of the Autism Society of San Francisco.

Michael Rosanoff, an epidemiologist who is the director for public health research for Autism Speaks, an advocacy group, said that the new number “is likely a more accurate representation of autism prevalence in the United States" than the 1 in 68 number.

"This means that 2 percent of children in the U.S. are living with autism," Rosanoff said in a statement."The earlier they have access to care, services and treatment, the more likely they are to progress."

The study also found that children diagnosed with autism had high rates of co-occurring conditions. Learning disabilities were the most common with 62.6 percent of children with autism also having LDs. Next highest was attention-deficit/hyperactivity disorder or ADHD with 42.8 percent of those with autism also having ADHD.

About 14 percent of those diagnosed need help with personal care, 9.1 percent reported they have trouble hearing and 7.3 percent that they have trouble seeing.

Nearly 60 percent received special education or early intervention services.

Below is a look at who is being diagnosed with autism.

As in previous years, most of the children being diagnosed with autism are male, non-Hispanic white, living in large metropolitan areas, with two parents and with at least one parent with more than a high school education. Many more boys are being diagnosed with autism than girls but the gap is narrowing somewhat. In 2011-2013 81.7 percent of all children diagnosed were male while 18.3 were female. In 2014, it was 75 percent male, 25 percent female. Most of the children being diagnosed with autism were identified by their parents as non-Hispanic white. More than two-thirds of children being diagnosed lived with two parents. Children being diagnosed represented a wide range of incomes. Most of the children being diagnosed had at least one parent with more than a high school education -- a phenomenon that experts have said could be due to the fact that they may be more likely to notice issues early on and seek medical help. More than half of children diagnosed live in large metropolitan statistical areas that include places like New York, Los Angeles and Washington, D.C.The children being diagnosed are spread out all over the country.

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New survey method finds more kids with autism
New survey finds 1 in 45 kids has autism: What's behind the alarming number?
November 13, 2015
NBC News.com Kids Health & The Today Show

BY: Maggie Fox
http://www.nbcnews.com/health/kids-health/new-survey-finds-1-45-kids-has-autism-n462596
http://www.today.com/health/new-survey-finds-1-45-kids-has-autism-whats-behind-t55731
A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism and parents are far more likely than in years past to seek a diagnosis for their kids.

"One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an

impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study.

We feel we are asking the question in a better way than before."

It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often.

"We feel we are asking the question in a better way than before."

Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism.

"The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday.

"In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote.

"It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S."

Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Hard to define

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a big range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to one in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well.

Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40 years ago.

"These kids have always been there," Alderman told NBC News.

"I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid."

Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said.

Money follows diagnosis

Now autism is something commonly talked about, and there's growing evidence that kids can be helped.

"There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis."

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism."

Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree.

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or.... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services."

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How changing a questionnaire nearly doubled America's autism rate
November 13, 2015
Bloomberg Business

BY: John Tozzi
http://www.bloomberg.com/news/articles/2015-11-13/autism-rate-nearly-doubles-on-paper-after-a-survey-is-changed
Adding a more detailed question led more parents to report that their children had the diagnosis. About 1.25 percent of kids in the U.S. had a diagnosis of autism spectrum disorder from 2011 to 2013, according to the National Health Interview Survey. In 2014, it was 2.24 percent -- a colossal move, in statistical terms. That doesn't mean an extra 600,000 kids developed autism last year. The difference is explained by a change in the order of questions and other adjustments in the 2014 survey, the Centers for Disease Control reports today. The statistical hiccup is a lesson in the difficulty of measuring health in the general population. It's especially hard for conditions like autism -- a developmental disorder marked by difficulty in communicating and socializing -- that have had shifting diagnostic criteria. The federal government has been using the National Health Interview Survey, intended to be nationally representative of U.S. households, since 1957. Surveyors visit people at home and ask questions about household members of all ages. Parents answer for their children. In recent years, the survey has questioned families of about 11,000 kids age 3 to 17 on autism and other developmental delays. In 2011 through 2013, surveyors asked parents whether doctors had ever told them their child had an intellectual disability, and then asked about any other developmental delays. Then they provided a list of 10 conditions, including autism alongside diabetes, arthritis, and others, and asked the parents to tell them which, if any, their child had. In 2014, rather than including autism on a list of other conditions, the survey inserted a question specifically about autism spectrum disorders. It came after the question about intellectual disabilities and before the question about other developmental delays. That apparently led some parents who might have previously chosen "other developmental delay" to indicate an autism diagnosis instead.There were big swings in the responses about autism and other developmental delays after the survey changed. But when researchers looked at the total number of people who responded yes to either question, there was very little difference: The more direct autism question "is likely to receive more attention and more thoughtful responses," authors from the CDC's National Center for Health Statistics write. So it's probably capturing diagnoses the earlier surveys

missed. "True year-to-year changes of the magnitude observed are unusual," the authors note, "and require abrupt or dramatic changes in the risk factors acting on the population."

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You won't guess why U.S. autism prevalence is now 1 in 45
November 13, 2015
Forbes

BY: Emily Willingham
http://www.forbes.com/sites/emilywillingham/2015/11/13/you-wont-guess-why-u-s-autism-prevalence-is-now-1-in-45/
Is it vaccines? Air pollution? Infections?

Nope. The reason that the latest numbers for autism prevalence among US children have climbed traces largely to a simple change in how interviewers asked a question.

The US Centers for Disease Control and Prevention last conducted the National Health Interview Survey (NHIS) for the years 2011 through 2013. The 2014 survey, though, included a tweak, and that tweak is the reason that autism prevalence climbed from 1.25% to 2.24% in 2014. Not even the most die-hard causation theorist could argue that in a single year or handful of years, something environmental, like vaccines, caused a near-doubling of autism prevalence in children ages 3 to 17 years.

So what underlies the increase?

For the 2011-2013 survey, parents answered a series of three questions. The first asked if their child had intellectual disability. The second asked if their child had any developmental delay. And the third question listed several conditions, from Down syndrome to sickle cell anemia to autism spectrum disorder (ASD), and parents were asked if their child had been diagnosed with any of them.

But 2014 brought some tweaks, and those tweaks made a difference. The intellectual disability question came first again. But the second question directly asked parents if their child had an ASD diagnosis. The third question then asked about any other developmental delay. More than 10,000 parents are interviewed in each year of this survey.

The simple change to emphasize the autism question resulted in the near doubling of prevalence from 2011–2013 to 2014. Underscoring that this increase reflects a shift in how parents responded to the questions, the prevalence of 'other developmental disorders' dropped in that same time period from 4.84% in 2011-2013 to 3.57% in 2014. Intellectual disability prevalence remained pretty much the same in the two periods, and the collective prevalence for all three conditions (intellectual disability, ASD, and other developmental disorders) also remained stable.

What a difference a question can make. But that might not have been the sole influence on the results.

Paul Lipkin, director of medical informatics at the Kennedy Krieger Institute and of the institute's Interactive Autism Network, sees the reordering and rewording of the questions as one factor. The changes place a "higher priority on identifying autism," he said in an email, but "at the same time, we know that professionals, parents, and the public also are more attuned to ASD and its identification at all ages."

These latest values bring the results of three national surveys of autism prevalence into alignment. In addition to the NHIS, the US also identifies autism prevalence values from the Autism and Developmental Disabilities Monitoring Network (ADDM) and the National Survey of Children's Health (NSCH). The most recent results from the NSCH put autism prevalence at 1 in 50 children. This latest NHIS prevalence of 1 in 45 converges on that finding, and the agreement among the studies strengthens their conclusions.

Lipkin noted that the advantages of the NHIS study are that it doesn't involve preselecting households for autism or other developmental conditions and samples across ages, unlike ADDM, which focuses on 8-year-olds.

The 2.24% prevalence also is remarkably close to the 2.64% reported in a thorough investigation of autism prevalence in the South Korean population. Lipkin sees that similarity as pointing to the universality of autism. “This is not a function of professional practice, cultural differences in parenting, or differing parental perspectives on their children,” he said.

The report also shows some stabilizing of previous disparities and a closing gap between girls and boys diagnosed with autism. Earlier surveys and some research have suggested that autism is four or five times more common in boys than in girls, but the NHIS survey has it as just under 3 times more common in boys (3.29 vs 1.15 in girls).

Some of the gaps among ethnicities also appear to be narrowing: ASD prevalence among non-Hispanic white children was 2.55 in the NHIS survey and 2.21 among non-Hispanic blacks, but still lower among Hispanic children at 1.49. Prevalence also is lower among uninsured families, possibly reflecting an access issue.

One final result to highlight from this survey: The results are similar for age groups, at 2.34 for children ages 3-10 and 2.13 for children ages 11-17. That similarity also suggests some stability across the years in the true prevalence of this condition, whether a child was born in 1998 or in the 21st century.

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Autism rate doubles in US to one in 45 kids: survey
November 13, 2015
Agence France Presse

BY: Franck Fife
http://www.afp.com/en/news/autism-rate-doubles-us-one-45-kids-survey
Autism affects one in 45 children in the United States, almost twice the rate from a few years ago, said a survey Friday that uses a new approach to assess the frequency of the developmental disorder.

The latest figures may reflect a more accurate picture of autism spectrum disorder, said the report by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, and so does not necessarily mean that there is a ballooning autism epidemic.

In fact, the study found that while autism spectrum diagnoses are more frequent than in the past, the overall number of people affected by neurodevelopmental problems has not risen, but has remained steady over time.

"What we call an autism spectrum disorder now is a much wider group of symptoms than what we called autism in the past so I think that captures a larger number of children that might have received other diagnoses in the past," said Katie Walton, an autism researcher who was not involved with the CDC survey.

"There have been some significant changes in the way that they are asking the questions," added Walton, a psychologist at the Ohio State University's Nisonger Center.

The report found that in 2014, one in 45 children had autism spectrum disorder, or 2.24 percent.

When the survey was given in 2011-2013, one in 80 children was diagnosed with ASD (1.25 percent).

The prevalence of autism in the United States was just one in 5,000 in 1975, and has been rising steadily in recent years.

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people. It is believed to be influenced by genetic and environmental factors, though scientists do not fully understand all its causes.

There is no known cure, but early intervention in toddlers as young as two can sometimes help.

There is no known cure for autism, but early intervention can be beneficial

Officials changed the order of the questions posed in the latest survey, completed by more than 11,000 parents, a process that may have resulted in more of them acknowledging a diagnosis of ASD.

"The question wording was expanded to include more specific details on what constituted an autism spectrum disorder," said the report.

Since the United States does not maintain national health registries, telephone surveys are among the ways that experts assess the rate of autism.

School and medical records have also been used to project a nationwide autism rate of one in 68 children, according to another CDC report issued in 2014.

- 'No epidemic' -

Some experts agree that these surveys do not suggest there is a worsening epidemic of autism in the United States.

A study out earlier this year led by Santhosh Girirajan, assistant professor of biochemistry and molecular biology and of anthropology at Penn State, found that the rising rate of autism seen in recent years resulted from reclassifying individuals with related neurological disorders.

His study analyzed 11 years of special-education enrollment data on an average of 6.2 million children per year, and found "no overall increase in the number of students enrolled in special education."

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people

Asked for comment on Friday's figures, he told AFP that the CDC's latest approach is an improvement.

"When people say (there is an) epidemic of autism, I am not really sure," he said.

"It is true that they are identifying more individuals with autism because autism is occurring with other disorders," he added.

Better diagnoses -- and improved strategies for estimating prevalence -- may be useful to parents who want to get improved treatment for their children at an early age, added Walton.

"I think people should understand that autism is a relatively common condition at this point and if you are concerned about your child... there are an increasing number of services out there," she said.

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1 in 45 U.S. kids has an autism spectrum disorder
November 13, 2015
LiveScience.com

BY: Cari Nierenberg
http://www.livescience.com/52790-autism-spectrum-disorder-prevalence-us-2014.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has

likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

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New estimate shows more American children with autism
November 13, 2015
WSB TV-2 (Atlanta)

BY: Associated Press contributed
http://www.wsbtv.com/news/news/local/new-estimate-shows-more-american-children-autism/npMm9/
A new government estimate shows autism is more common— 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common.

The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children.

The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children.

The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added.

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CDC survey finds autism on the rise
November 13, 2015
Disability Scoop
BY:Michelle Diament

Autism may affect as many as 1 in 45 American children, according to a new government survey.

In a report released Friday, the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics said that as of 2014, some 2.24 percent of American kids had received a diagnosis on the spectrum.

The figures come from the National Health Interview Survey, which last year asked 11,000 parents of kids ages 3 to 17 across the country if they were ever told by a doctor or health professional that their child had autism, intellectual disability or other developmental disabilities.

By comparison, similar data from 2011 to 2013 found an autism prevalence rate of 1.25 percent, the report indicated.

Despite a large uptick in reported autism prevalence, however, researchers with the National Center for Health Statistics said the variation is likely due in part to changes in the way the survey asked about autism.

"In previous years, it is likely that some parents of children diagnosed with ASD reported this developmental disability as other DD instead of, or in addition to, ASD," they wrote.

The survey is also just one of a handful of methods the government uses to measure autism prevalence. Findings from a different study — which regularly assesses medical and educational records of 8-year-olds in various pockets of the country — are still considered the CDC's official estimate. That study most recently concluded that 1 in 68 American children have autism.

Aside from autism, the 2014 survey found that the prevalence of intellectual disability remained largely unchanged at 1.1 percent. However, the number of children with other developmental disabilities declined sharply to 3.57 percent in 2014, down from 4.84 percent in the 2011 to 2013 data, the report said.

When combined, researchers said the prevalence of children with all developmental disabilities "did not differ significantly" in the 2014 survey compared to the previous years.

Public Social Media Activity
11/13-16/15

Higher autism rate is due to changes in reporting, not kids http://s.einnews.com/l-B20P_D79 - @EINAutismNews

Survey Questions May Be Cause of Jump In Autism Statistics, Experts Say http://dlvr.it/Cm0Ntc - @EastonDV

CDC releases newest estimate on US children born with autism - @TravisCMS

New Official Number Of American Children With Autism Stirs Controversy #Oklahoma http://www.newslocker.com/en-us/region/oklahoma/new-official-number-of-american-children-with-autism-stirs-controversy/ ... - @OklahomaUS_nws

Survey Finds Big Increase in Number of Kids Estimated to Have Autism - CNBC | @scoopit http://sco.lt/98DDeL - @MarkEDeschaine

U.S. survey shows higher rate of autism in children http://reut.rs/1OJf14T via @Reuters http://ow.ly/i/evyzk - @RivCoDoc

What do those new autism numbers really mean? @ejwillingham explains. http://www.forbes.com/sites/emilywillingham/2015/11/13/you-wont-guess-why-u-s-autism-prevalence-is-now-1-in-45/ ... - @stevessilberman

Study finds one in 45 kids has autism, http://usat.ly/1kSW3M9 - @LizSzabo

From: Schieve, Laura (CDC/ONDIEH/NCBDDD)
Sent: Sat, 14 Nov 2015 11:09:46 -0500
To: Moussakhani, Nisha (CDC/OID/NCHHSTP); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Mitchell, Betsy (CDC/ONDIEH/NCBDDD); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD); Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD); Atkins, Bret (CDC/ONDIEH/NCBDDD); Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR); Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR); Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR); Chaney, Sascha (CDC/ONDIEH/NCEH); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Hunter, Karen (CDC/ONDIEH/NCBDDD); Chan, C. Leah (CDC/ONDIEH/NCBDDD); Maenner, Matthew J. (CDC/ONDIEH/NCBDDD); Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Gonzalez, Belsie (CDC/OD/OADC)
Subject: RE: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

Thanks so much!

From: Moussakhani, Nisha (CDC/OID/NCHHSTP)
Sent: Friday, November 13, 2015 5:00 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD) <smd3@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR) <xbf4@cdc.gov>; Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR) <yhy8@cdc.gov>; Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR) <koo6@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Schieve, Laura (CDC/ONDIEH/NCBDDD) <ljs9@cdc.gov>; Maenner, Matthew J. (CDC/ONDIEH/NCBDDD) <xde8@cdc.gov>; Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR) <max8@cdc.gov>
Cc: Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Subject: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

All,
We have been following media and social media coverage today regarding the NCHS report: *"Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey".* Please find below and attached coverage. Overall, many agree that the headlines aren't ideal but the majority of the reporting covers nicely our message and the differentiation between surveys/survey results and what they mean. I have highlighted for you where CDC is quoted in yellow highlight below.

We will continue to monitor activity over the weekend and early next week – sending you updates as soon as possible.

Late next week after media activity has slowed, we can look for the gaps/lessons learned in messaging across these reports and do a more in-depth analysis that will help improve our messaging even further in preparation for the ADDM release in March, 2016.

Thank you and have a great weekend!
--Nisha

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NCHS Report on Autism Prevalence: Coverage Compilation
As of November 13th @ 4:45pm

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CDC COVERAGE

Study finds more than 2% of children have autism
November 13, 2015
USA Today

BY: Liz Szabo
http://www.usatoday.com/story/news/2015/11/13/study-finds-more-than-2-children-have-autism/75673774/

A new survey has found a big jump in the number of children with autism, although researchers caution that the increase is likely due to the way that questions were asked. More than 2.2% of children ages 3 to 17 — about one in 45 — have autism, according to the Center for Disease Control and Prevention's National Health Interview Survey, conducted in 2014. The annual survey found autism rates of 1.25%, or one in 80 people, from 2011 to 2013.

People with autism — a complex condition of brain development — tend to have difficulty with social interaction and verbal and nonverbal communications and are prone to repetitive behaviors. While the CDC report describes autism as a development disability, some people with autism say they are simply different, rather than disabled.

The dramatic increase in autism rates in the latest survey suggests that parents used different labels to describe their children than in earlier years, said Katherine Walton, an assistant professor of psychiatry

and psychology at Ohio State University, who wasn't involved in the new study. While the number of children diagnosed with autism went up, the number reporting children diagnosed with "other development delays" went down. Yet the overall number of parents who reported any developmental disability in their kids — about 5.75% — remained the same.

Parents may have changed the way they labeled their children because of changes made to the way that researchers interviewed them, said study coauthor Benjamin Zablotsky, a researcher at the CDC's National Center for Health Statistics. Different surveys have produced varying autism rates. The new survey results are similar to those of one released in 2013, which found 2% of children had autism. A study released in 2014 found the autism rate closer to 1.5%. Although studies have found rising rates of autism for two decades, there is no clear explanation why. It's possible that more children are developing the condition, Walton said. But she notes that the definition of autism is much broader today than it was decades ago. People also are more aware of autism, leading to increased testing of younger children. Multiple studies have ruled out vaccines as a cause of autism. Alison Singer, whose daughter has autism, said she's less interested in estimating the prevalence of autism than in securing support and services for her child. "As parents, we're not interested in '1 in 80' or '1 in 100.' We're interested in *our* one," said Singer, president of the Autism Science Foundation. "We're interested in getting access to services, making sure that children are in the appropriate classrooms and that adults with autism receive supported housing and employment, and that we're funding research to find the cause."

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Latest U.S. estimate suggests 1 in 45 children have autism
November 13, 2015
ABC News

BY: Mike Stobbe AP
http://abcnews.go.com/Health/wireStory/latest-us-estimate-suggests-45-children-autism-35171198

The government has a new estimate for autism — 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common. The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children. The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children. The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added. Estimates of how common autism is have been steadily increasing. In 2007, the CDC estimated 1 in 150 children had autism. For decades, autism meant kids with severe language, intellectual and social impairments and unusual, repetitious behaviors. But the definition has gradually expanded and now includes milder, related conditions. The cause or causes of autism are still not known. Experts say teachers and parents are increasingly likely to say a child with learning and behavior problems is autistic, so at least some of the apparent increase is due to different labeling. A third CDC survey issued two years ago — also based on parents' responses — came up with an estimate of 1 in 50 children with autism.

In the latest survey, some questions about autism were reworded to try to avoid confusion and get a more accurate figure, said lead author, Benjamin Zablotsky. "I think we'll continue to see the estimates getting closer" to each other, he said.

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Survey finds big increase in number of kids estimated to have autism

November 13, 2015
CNBC

BY: Maggie Fox
http://www.cnbc.com/2015/11/13/survey-finds-big-increase-in-number-of-kids-estimated-to-have-autism.html

A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism, and that parents are far more likely than in years past to seek a diagnosis for their kids. "One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study. "We feel we are asking the question in a better way than before," he said. It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often. Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism. "The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday. "In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote. "It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S." Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a large range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to 1 in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well. Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40 years ago. "These kids have always been there," Alderman told NBC News. "I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid." Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said. Now autism is something commonly talked about, and there's growing evidence that kids can be helped. "There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis." Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree. "Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or ... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services." Wiznitzer agrees that kids now diagnosed with autism would have had "another label" in the past. "We're just changing a child's diagnosis from, let's say, intellectual disability and mental retardation to autism spectrum disorder," he said. "Certainly one reason for the increase over time is that parents do come seeking the diagnosis," Shulman added. The findings fit in with other studies seeking to show whether autism is actually occurring more frequently, or simply being recognized and diagnosed more often. A team at Penn State University also found that children are being reclassified from something broad, like pervasive developmental disorder, to the more specific autism. And the NCHS found earlier this year that as many as 9 percent of children diagnosed with autism don't actually have it.

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1 in 45 American children has an autism spectrum disorder
November 13, 2015
Fox News Health

BY: Cari Nierenberg
http://www.foxnews.com/health/2015/11/13/1-in-45-american-children-has-autism-spectrum-disorder.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist

in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

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Autism cases in U.S. jump to 1 in 45: Who gets the diagnosis, in 8 simple charts
November 13, 2015
The Washington Post

BY: Ariana Eunjung Cha
https://www.washingtonpost.com/news/to-your-health/wp/2015/11/13/autism-cases-in-u-s-rise-to-1-in-45-a-look-at-who-gets-the-diagnosis-in-8-simple-charts/
The number of autism cases in the United States appeared to jump dramatically in 2014 according to new estimates released Friday, but researchers said that changes in the format of the questionnaire likely affected the numbers.

The report from the Centers for Disease Control and Prevention and National Center for Health Statistics shows that the prevalence of autism in children ages 3 to 17 went up nearly 80 percent from 2011-2013 to 2014. Instead of 1 in 68 children having autism -- a number that has alarmed public health officials in recent years and strained state and school system resources -- researchers now estimate that the prevalence is now 1 in 45.

Lead author Benjamin Zablotsky, an epidemiologist at the NCHS, and his colleagues said that in previous years some parents of children diagnosed with autism spectrum disorder likely reported it as a developmental disability instead of or in addition to autism because it was listed first. The new questionnaire flips the two categories, which researchers said made the autism estimates more similar to ones from other sources.

As might be expected from this change, the prevalence of other developmental disabilities declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent in 2014.

The prevalence of intellectual disability did not significantly change and remains at 1.1 percent and the prevalence of any three of the conditions was constant across all surveys.

The high rates of autism among American children has been the source of much debate in recent years, with some experts attributing it to overdiagnosis and others expressing concern about possible environmental factors affecting children's brain development.

“It’s not the year to year numbers that concern us. It’s the decade to decade. The fact that we have 1 in 45 children with a very serious neurological condition is a catastrophe by any measure,” said Jill Escher, president of the Autism Society of San Francisco.

Michael Rosanoff, an epidemiologist who is the director for public health research for Autism Speaks, an advocacy group, said that the new number “is likely a more accurate representation of autism prevalence in the United States" than the 1 in 68 number.

"This means that 2 percent of children in the U.S. are living with autism," Rosanoff said in a statement."The earlier they have access to care, services and treatment, the more likely they are to progress."

The study also found that children diagnosed with autism had high rates of co-occurring conditions. Learning disabilities were the most common with 62.6 percent of children with autism also having LDs. Next highest was attention-deficit/hyperactivity disorder or ADHD with 42.8 percent of those with autism also having ADHD.

About 14 percent of those diagnosed need help with personal care, 9.1 percent reported they have trouble hearing and 7.3 percent that they have trouble seeing.

Nearly 60 percent received special education or early intervention services.

Below is a look at who is being diagnosed with autism.

As in previous years, most of the children being diagnosed with autism are male, non-Hispanic white, living in large metropolitan areas, with two parents and with at least one parent with more than a high school education. Many more boys are being diagnosed with autism than girls but the gap is narrowing somewhat. In 2011-2013 81.7 percent of all children diagnosed were male while 18.3 were female. In 2014, it was 75 percent male, 25 percent female. Most of the children being diagnosed with autism were identified by their parents as non-Hispanic white. More than two-thirds of children being diagnosed lived with two parents. Children being diagnosed represented a wide range of incomes. Most of the children being diagnosed had at least one parent with more than a high school education -- a phenomenon that experts have said could be due to the fact that they may be more likely to notice issues early on and seek medical help. More than half of children diagnosed live in large metropolitan statistical areas that include places like New York, Los Angeles and Washington, D.C.The children being diagnosed are spread out all over the country.

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New survey finds 1 in 45 kids has autism: What's behind the alarming number?
November 13, 2015
NBC News.com Kids Health & The Today Show

BY: Maggie Fox
http://www.nbcnews.com/health/kids-health/new-survey-finds-1-45-kids-has-autism-n462596
http://www.today.com/health/new-survey-finds-1-45-kids-has-autism-whats-behind-t55731
A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism and parents are far more likely than in years past to seek a diagnosis for their kids.

"One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study.

We feel we are asking the question in a better way than before."

It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often.

"We feel we are asking the question in a better way than before."

Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism.

"The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday.

"In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote.

"It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S."

Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Hard to define

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a big range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to one in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well.

Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40 years ago.

"These kids have always been there," Alderman told NBC News.

"I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid."

Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said.

Money follows diagnosis

Now autism is something commonly talked about, and there's growing evidence that kids can be helped.

"There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis."

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism."

Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree.

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or.... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services."

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How changing a questionnaire nearly doubled America's autism rate
November 13, 2015
Bloomberg Business

BY: John Tozzi
http://www.bloomberg.com/news/articles/2015-11-13/autism-rate-nearly-doubles-on-paper-after-a-survey-is-changed
Adding a more detailed question led more parents to report that their children had the diagnosis. About 1.25 percent of kids in the U.S. had a diagnosis of autism spectrum disorder from 2011 to 2013, according to the National Health Interview Survey. In 2014, it was 2.24 percent -- a colossal move, in statistical terms. That doesn't mean an extra 600,000 kids developed autism last year. The difference is explained by a change in the order of questions and other adjustments in the 2014 survey, the Centers for Disease Control reports today. The statistical hiccup is a lesson in the difficulty of measuring health in the general population. It's especially hard for conditions like autism -- a developmental disorder marked by difficulty in communicating and socializing -- that have had shifting diagnostic criteria. The federal government has been using the National Health Interview Survey, intended to be nationally representative of U.S. households, since 1957. Surveyors visit people at home and ask questions about household members of all ages. Parents answer for their children. In recent years, the survey has questioned families of about 11,000 kids age 3 to 17 on autism and other developmental delays. In 2011 through 2013, surveyors asked parents whether doctors had ever told them their child had an intellectual disability, and then asked about any other developmental delays. Then they provided a list of 10 conditions, including autism alongside diabetes, arthritis, and others, and asked the parents to tell them which, if any, their child had. In 2014, rather than including autism on a list of other conditions, the survey inserted a question specifically about autism spectrum disorders. It came after the question about intellectual disabilities and before the question about other developmental delays. That apparently led some parents who might have previously chosen "other developmental delay" to indicate an autism diagnosis instead.There were big swings in the responses about autism and other developmental delays after the survey changed. But when researchers looked at the total number of people who responded yes to either question, there was very little difference: The more direct autism question "is likely to receive more attention and more thoughtful responses," authors from the CDC's National Center for Health Statistics write. So it's probably capturing diagnoses the earlier surveys missed. "True year-to-year changes of the magnitude observed are unusual," the authors note, "and require abrupt or dramatic changes in the risk factors acting on the population."

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You won't guess why U.S. autism prevalence is now 1 in 45
November 13, 2015
Forbes

BY: Emily Willingham
http://www.forbes.com/sites/emilywillingham/2015/11/13/you-wont-guess-why-u-s-autism-prevalence-is-now-1-in-45/
Is it vaccines? Air pollution? Infections?

Nope. The reason that the latest numbers for autism prevalence among US children have climbed traces largely to a simple change in how interviewers asked a question.

The US Centers for Disease Control and Prevention last conducted the National Health Interview Survey (NHIS) for the years 2011 through 2013. The 2014 survey, though, included a tweak, and that tweak is the reason that autism prevalence climbed from 1.25% to 2.24% in 2014. Not even the most die-hard causation theorist could argue that in a single year or handful of years, something environmental, like vaccines, caused a near-doubling of autism prevalence in children ages 3 to 17 years.

So what underlies the increase?

For the 2011-2013 survey, parents answered a series of three questions. The first asked if their child had intellectual disability. The second asked if their child had any developmental delay. And the third question listed several conditions, from Down syndrome to sickle cell anemia to autism spectrum disorder (ASD), and parents were asked if their child had been diagnosed with any of them.

But 2014 brought some tweaks, and those tweaks made a difference. The intellectual disability question came first again. But the second question directly asked parents if their child had an ASD diagnosis. The third question then asked about any other developmental delay. More than 10,000 parents are interviewed in each year of this survey.

The simple change to emphasize the autism question resulted in the near doubling of prevalence from 2011–2013 to 2014. Underscoring that this increase reflects a shift in how parents responded to the questions, the prevalence of 'other developmental disorders' dropped in that same time period from 4.84% in 2011-2013 to 3.57% in 2014. Intellectual disability prevalence remained pretty much the same in the two periods, and the collective prevalence for all three conditions (intellectual disability, ASD, and other developmental disorders) also remained stable.

What a difference a question can make. But that might not have been the sole influence on the results.

Paul Lipkin, director of medical informatics at the Kennedy Krieger Institute and of the institute's Interactive Autism Network, sees the reordering and rewording of the questions as one factor. The changes place a "higher priority on identifying autism," he said in an email, but "at the same time, we know that professionals, parents, and the public also are more attuned to ASD and its identification at all ages."

These latest values bring the results of three national surveys of autism prevalence into alignment. In addition to the NHIS, the US also identifies autism prevalence values from the Autism and Developmental Disabilities Monitoring Network (ADDM) and the National Survey of Children's Health (NSCH). The most recent results from the NSCH put autism prevalence at 1 in 50 children. This latest NHIS prevalence of 1 in 45 converges on that finding, and the agreement among the studies strengthens their conclusions.

Lipkin noted that the advantages of the NHIS study are that it doesn't involve preselecting households for autism or other developmental conditions and samples across ages, unlike ADDM, which focuses on 8-year-olds.

The 2.24% prevalence also is remarkably close to the 2.64% reported in a thorough investigation of autism prevalence in the South Korean population. Lipkin sees that similarity as pointing to the

universality of autism. “This is not a function of professional practice, cultural differences in parenting, or differing parental perspectives on their children,” he said.

The report also shows some stabilizing of previous disparities and a closing gap between girls and boys diagnosed with autism. Earlier surveys and some research have suggested that autism is four or five times more common in boys than in girls, but the NHIS survey has it as just under 3 times more common in boys (3.29 vs 1.15 in girls).

Some of the gaps among ethnicities also appear to be narrowing: ASD prevalence among non-Hispanic white children was 2.55 in the NHIS survey and 2.21 among non-Hispanic blacks, but still lower among Hispanic children at 1.49. Prevalence also is lower among uninsured families, possibly reflecting an access issue.

One final result to highlight from this survey: The results are similar for age groups, at 2.34 for children ages 3-10 and 2.13 for children ages 11-17. That similarity also suggests some stability across the years in the true prevalence of this condition, whether a child was born in 1998 or in the 21st century.

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Autism rate doubles in US to one in 45 kids: survey
November 13, 2015
Agence France Presse

BY: Franck Fife
http://www.afp.com/en/news/autism-rate-doubles-us-one-45-kids-survey
Autism affects one in 45 children in the United States, almost twice the rate from a few years ago, said a survey Friday that uses a new approach to assess the frequency of the developmental disorder.

The latest figures may reflect a more accurate picture of autism spectrum disorder, said the report by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, and so does not necessarily mean that there is a ballooning autism epidemic.

In fact, the study found that while autism spectrum diagnoses are more frequent than in the past, the overall number of people affected by neurodevelopmental problems has not risen, but has remained steady over time.

"What we call an autism spectrum disorder now is a much wider group of symptoms than what we called autism in the past so I think that captures a larger number of children that might have received other diagnoses in the past," said Katie Walton, an autism researcher who was not involved with the CDC survey.

"There have been some significant changes in the way that they are asking the questions," added Walton, a psychologist at the Ohio State University's Nisonger Center.

The report found that in 2014, one in 45 children had autism spectrum disorder, or 2.24 percent.

When the survey was given in 2011-2013, one in 80 children was diagnosed with ASD (1.25 percent).

The prevalence of autism in the United States was just one in 5,000 in 1975, and has been rising steadily in recent years.

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people. It is believed to be influenced by genetic and environmental factors, though scientists do not fully understand all its causes.

There is no known cure, but early intervention in toddlers as young as two can sometimes help.

There is no known cure for autism, but early intervention can be beneficial

Officials changed the order of the questions posed in the latest survey, completed by more than 11,000 parents, a process that may have resulted in more of them acknowledging a diagnosis of ASD.

"The question wording was expanded to include more specific details on what constituted an autism spectrum disorder," said the report.

Since the United States does not maintain national health registries, telephone surveys are among the ways that experts assess the rate of autism.

School and medical records have also been used to project a nationwide autism rate of one in 68 children, according to another CDC report issued in 2014.

- 'No epidemic' -

Some experts agree that these surveys do not suggest there is a worsening epidemic of autism in the United States.

A study out earlier this year led by Santhosh Girirajan, assistant professor of biochemistry and molecular biology and of anthropology at Penn State, found that the rising rate of autism seen in recent years resulted from reclassifying individuals with related neurological disorders.

His study analyzed 11 years of special-education enrollment data on an average of 6.2 million children per year, and found "no overall increase in the number of students enrolled in special education."

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people

Asked for comment on Friday's figures, he told AFP that the CDC's latest approach is an improvement.

"When people say (there is an) epidemic of autism, I am not really sure," he said.

"It is true that they are identifying more individuals with autism because autism is occurring with other disorders," he added.

Better diagnoses -- and improved strategies for estimating prevalence -- may be useful to parents who want to get improved treatment for their children at an early age, added Walton.

"I think people should understand that autism is a relatively common condition at this point and if you are concerned about your child... there are an increasing number of services out there," she said.

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1 in 45 U.S. kids has an autism spectrum disorder
November 13, 2015
LiveScience.com

BY: Cari Nierenberg
http://www.livescience.com/52790-autism-spectrum-disorder-prevalence-us-2014.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has

likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

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New estimate shows more American children with autism
November 13, 2015
WSB TV-2 (Atlanta)

BY: Associated Press contributed
http://www.wsbtv.com/news/news/local/new-estimate-shows-more-american-children-autism/npMm9/
A new government estimate shows autism is more common— 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common.

The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children.

The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children.

The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added.

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CDC survey finds autism on the rise
November 13, 2015
Disability Scoop
BY:Michelle Diament

Autism may affect as many as 1 in 45 American children, according to a new government survey.

In a report released Friday, the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics said that as of 2014, some 2.24 percent of American kids had received a diagnosis on the spectrum.

The figures come from the National Health Interview Survey, which last year asked 11,000 parents of kids ages 3 to 17 across the country if they were ever told by a doctor or health professional that their child had autism, intellectual disability or other developmental disabilities.

By comparison, similar data from 2011 to 2013 found an autism prevalence rate of 1.25 percent, the report indicated.

Despite a large uptick in reported autism prevalence, however, researchers with the National Center for Health Statistics said the variation is likely due in part to changes in the way the survey asked about autism.

"In previous years, it is likely that some parents of children diagnosed with ASD reported this developmental disability as other DD instead of, or in addition to, ASD," they wrote.

The survey is also just one of a handful of methods the government uses to measure autism prevalence. Findings from a different study — which regularly assesses medical and educational records of 8-year-olds in various pockets of the country — are still considered the CDC's official estimate. That study most recently concluded that 1 in 68 American children have autism.

Aside from autism, the 2014 survey found that the prevalence of intellectual disability remained largely unchanged at 1.1 percent. However, the number of children with other developmental disabilities declined sharply to 3.57 percent in 2014, down from 4.84 percent in the 2011 to 2013 data, the report said.

When combined, researchers said the prevalence of children with all developmental disabilities "did not differ significantly" in the 2014 survey compared to the previous years.

From: Moussakhani, Nisha (CDC/OID/NCHHSTP)
Sent: Mon, 16 Nov 2015 09:00:47 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

My pleasure, Colleen! And, I'm working on an updated compilation of media coverage and will send to you and leadership by COB today.
Nisha

Nisha Moussakhani, MPH
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From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, November 13, 2015 5:16 PM
To: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD) <smd3@cdc.gov>; Moussakhani, Nisha (CDC/OID/NCHHSTP) <gtq1@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR) <xbf4@cdc.gov>; Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR) <yhy8@cdc.gov>; Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR) <koo6@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Schieve, Laura (CDC/ONDIEH/NCBDDD) <ljs9@cdc.gov>; Maenner, Matthew J. (CDC/ONDIEH/NCBDDD) <xde8@cdc.gov>; Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR) <max8@cdc.gov>
Cc: Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Subject: RE: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

Yes, very nice summary! Thanks all

From: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Sent: Friday, November 13, 2015 5:04 PM

To: Moussakhani, Nisha (CDC/OID/NCHHSTP) <gtq1@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR) <xbf4@cdc.gov>; Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR) <yhy8@cdc.gov>; Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR) <koo6@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Schieve, Laura (CDC/ONDIEH/NCBDDD) <ljs9@cdc.gov>; Maenner, Matthew J. (CDC/ONDIEH/NCBDDD) <xde8@cdc.gov>; Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR) <max8@cdc.gov>
Cc: Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Subject: RE: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

Nicely done, thank you Nisha.

From: Moussakhani, Nisha (CDC/OID/NCHHSTP)
Sent: Friday, November 13, 2015 5:00 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD) <smd3@cdc.gov>; Mitchell, Betsy (CDC/ONDIEH/NCBDDD) <bhm0@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Mann, Mario C. (CDC/ONDIEH/NCBDDD) (CTR) <xbf4@cdc.gov>; Thrasher, Janelle (CDC/ONDIEH/NCBDDD) (CTR) <yhy8@cdc.gov>; Mayes, Joseph (Joey) (CDC/ONDIEH/NCBDDD) (CTR) <koo6@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Moore, Cynthia (CDC/ONDIEH/NCBDDD) <cam0@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Schieve, Laura (CDC/ONDIEH/NCBDDD) <ljs9@cdc.gov>; Maenner, Matthew J. (CDC/ONDIEH/NCBDDD) <xde8@cdc.gov>; Miller, Marianne (CDC/ONDIEH/NCBDDD) (CTR) <max8@cdc.gov>
Cc: Gonzalez, Belsie (CDC/OD/OADC) <fqi1@cdc.gov>
Subject: Compilation of Coverage: NCHS Autism Prevalence Report Release, 11/13/15

All,
We have been following media and social media coverage today regarding the NCHS report: *"Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey".* Please find below and attached coverage. Overall, many agree that the headlines aren't ideal but the majority of the reporting covers nicely our message and the differentiation between surveys/survey results and what they mean. I have highlighted for you where CDC is quoted in yellow highlight below.

We will continue to monitor activity over the weekend and early next week – sending you updates as soon as possible.

Late next week after media activity has slowed, we can look for the gaps/lessons learned in messaging across these reports and do a more in-depth analysis that will help improve our messaging even further in preparation for the ADDM release in March, 2016.

Thank you and have a great weekend!
--Nisha

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NCHS Report on Autism Prevalence: Coverage Compilation
As of November 13th @ 4:45pm

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CDC COVERAGE

Study finds more than 2% of children have autism
November 13, 2015
USA Today

BY: Liz Szabo
http://www.usatoday.com/story/news/2015/11/13/study-finds-more-than-2-children-have-autism/75673774/

A new survey has found a big jump in the number of children with autism, although researchers caution that the increase is likely due to the way that questions were asked. More than 2.2% of children ages 3 to 17 — about one in 45 — have autism, according to the Center for Disease Control and Prevention's National Health Interview Survey, conducted in 2014. The annual survey found autism rates of 1.25%, or one in 80 people, from 2011 to 2013.

People with autism — a complex condition of brain development — tend to have difficulty with social interaction and verbal and nonverbal communications and are prone to repetitive behaviors. While the CDC report describes autism as a development disability, some people with autism say they are simply different, rather than disabled.

The dramatic increase in autism rates in the latest survey suggests that parents used different labels to describe their children than in earlier years, said Katherine Walton, an assistant professor of psychiatry and psychology at Ohio State University, who wasn't involved in the new study. While the number of children diagnosed with autism went up, the number reporting children diagnosed with "other development delays" went down. Yet the overall number of parents who reported any developmental disability in their kids — about 5.75% — remained the same.

Parents may have changed the way they labeled their children because of changes made to the way that researchers interviewed them, said study coauthor Benjamin Zablotsky, a researcher at the CDC's National Center for Health Statistics. Different surveys have produced varying autism rates. The new survey results are similar to those of one released in 2013, which found 2% of children had autism. A study released in 2014 found the autism rate closer to 1.5%. Although studies have found rising rates of autism for two decades, there is no clear explanation why. It's possible that more children are developing the condition, Walton said. But she notes that the definition of autism is much broader today than it was decades ago. People also are more aware of autism, leading to increased testing of younger children. Multiple studies have ruled out vaccines as a cause of autism. Alison Singer, whose daughter has autism, said she's less interested in estimating the prevalence of autism than in securing support and services for her child. "As parents, we're not interested in '1 in 80' or '1 in 100.' We're interested in *our* one," said Singer, president of the Autism Science Foundation. "We're interested in getting access to services, making sure that children are in the appropriate classrooms and that adults with autism receive supported housing and employment, and that we're funding research to find the cause."

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Latest U.S. estimate suggests 1 in 45 children have autism
November 13, 2015
ABC News

BY: Mike Stobbe AP
http://abcnews.go.com/Health/wireStory/latest-us-estimate-suggests-45-children-autism-35171198

The government has a new estimate for autism — 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common. The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children. The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children. The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added. Estimates of how common autism is have been steadily increasing. In 2007, the CDC estimated 1 in 150 children had autism. For decades, autism meant kids with severe language, intellectual and social impairments and unusual, repetitious behaviors. But the definition has gradually expanded and now includes milder, related conditions. The cause or causes of autism are still not known. Experts say teachers and parents are increasingly likely to say a child with learning and behavior problems is autistic, so at least some of the apparent increase is due to different labeling. A third CDC survey issued two years ago — also based on parents' responses — came up with an estimate of 1 in 50 children with autism.

In the latest survey, some questions about autism were reworded to try to avoid confusion and get a more accurate figure, said lead author, Benjamin Zablotsky. "I think we'll continue to see the estimates getting closer" to each other, he said.

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Survey finds big increase in number of kids estimated to have autism
November 13, 2015
CNBC

BY: Maggie Fox

http://www.cnbc.com/2015/11/13/survey-finds-big-increase-in-number-of-kids-estimated-to-have-autism.html

A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism, and that parents are far more likely than in years past to seek a diagnosis for their kids. "One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study. "We feel we are asking the question in a better way than before," he said. It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often. Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism. "The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday. "In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote. "It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S." Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a large range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to 1 in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well. Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40

years ago. "These kids have always been there," Alderman told NBC News. "I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid." Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said. Now autism is something commonly talked about, and there's growing evidence that kids can be helped. "There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis." Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree. "Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or ... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services." Wiznitzer agrees that kids now diagnosed with autism would have had "another label" in the past. "We're just changing a child's diagnosis from, let's say, intellectual disability and mental retardation to autism spectrum disorder," he said. "Certainly one reason for the increase over time is that parents do come seeking the diagnosis," Shulman added. The findings fit in with other studies seeking to show whether autism is actually occurring more frequently, or simply being recognized and diagnosed more often. A team at Penn State University also found that children are being reclassified from something broad, like pervasive developmental disorder, to the more specific autism. And the NCHS found earlier this year that as many as 9 percent of children diagnosed with autism don't actually have it.

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1 in 45 American children has an autism spectrum disorder
November 13, 2015
Fox News Health

BY: Cari Nierenberg
http://www.foxnews.com/health/2015/11/13/1-in-45-american-children-has-autism-spectrum-disorder.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

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Autism cases in U.S. jump to 1 in 45: Who gets the diagnosis, in 8 simple charts
November 13, 2015
The Washington Post

BY: Ariana Eunjung Cha
https://www.washingtonpost.com/news/to-your-health/wp/2015/11/13/autism-cases-in-u-s-rise-to-1-in-45-a-look-at-who-gets-the-diagnosis-in-8-simple-charts/
The number of autism cases in the United States appeared to jump dramatically in 2014 according to new estimates released Friday, but researchers said that changes in the format of the questionnaire likely affected the numbers.

The report from the Centers for Disease Control and Prevention and National Center for Health Statistics shows that the prevalence of autism in children ages 3 to 17 went up nearly 80 percent from 2011-2013 to 2014. Instead of 1 in 68 children having autism -- a number that has alarmed public health officials in recent years and strained state and school system resources -- researchers now estimate that the prevalence is now 1 in 45.

Lead author Benjamin Zablotsky, an epidemiologist at the NCHS, and his colleagues said that in previous years some parents of children diagnosed with autism spectrum disorder likely reported it as a developmental disability instead of or in addition to autism because it was listed first. The new questionnaire flips the two categories, which researchers said made the autism estimates more similar to ones from other sources.

As might be expected from this change, the prevalence of other developmental disabilities declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent in 2014.

The prevalence of intellectual disability did not significantly change and remains at 1.1 percent and the prevalence of any three of the conditions was constant across all surveys.

The high rates of autism among American children has been the source of much debate in recent years, with some experts attributing it to overdiagnosis and others expressing concern about possible environmental factors affecting children's brain development.

“It’s not the year to year numbers that concern us. It’s the decade to decade. The fact that we have 1 in 45 children with a very serious neurological condition is a catastrophe by any measure,” said Jill Escher, president of the Autism Society of San Francisco.

Michael Rosanoff, an epidemiologist who is the director for public health research for Autism Speaks, an advocacy group, said that the new number “is likely a more accurate representation of autism prevalence in the United States" than the 1 in 68 number.

"This means that 2 percent of children in the U.S. are living with autism," Rosanoff said in a statement."The earlier they have access to care, services and treatment, the more likely they are to progress."

The study also found that children diagnosed with autism had high rates of co-occurring conditions. Learning disabilities were the most common with 62.6 percent of children with autism also having LDs. Next highest was attention-deficit/hyperactivity disorder or ADHD with 42.8 percent of those with autism also having ADHD.

About 14 percent of those diagnosed need help with personal care, 9.1 percent reported they have trouble hearing and 7.3 percent that they have trouble seeing.

Nearly 60 percent received special education or early intervention services.

Below is a look at who is being diagnosed with autism.

As in previous years, most of the children being diagnosed with autism are male, non-Hispanic white, living in large metropolitan areas, with two parents and with at least one parent with more than a high school education. Many more boys are being diagnosed with autism than girls but the gap is narrowing somewhat. In 2011-2013 81.7 percent of all children diagnosed were male while 18.3 were female. In 2014, it was 75 percent male, 25 percent female. Most of the children being diagnosed with autism were identified by their parents as non-Hispanic white. More than two-thirds of children being diagnosed lived with two parents. Children being diagnosed represented a wide range of incomes. Most of the children being diagnosed had at least one parent with more than a high school education -- a phenomenon that experts have said could be due to the fact that they may be more likely to notice issues early on and seek medical help. More than half of children diagnosed live in large metropolitan statistical areas that include places like New York, Los Angeles and Washington, D.C.The children being diagnosed are spread out all over the country.

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New survey finds 1 in 45 kids has autism: What's behind the alarming number?
November 13, 2015
NBC News.com Kids Health & The Today Show

BY: Maggie Fox
http://www.nbcnews.com/health/kids-health/new-survey-finds-1-45-kids-has-autism-n462596
http://www.today.com/health/new-survey-finds-1-45-kids-has-autism-whats-behind-t55731
A new government survey finds that more than 2 percent of U.S. kids have been diagnosed with autism — or 1 in 45 children aged 3 and older. That seems like a startling increase from the last estimate of 1 in 68 kids.

But the researchers are quick to point out that the latest survey was done in a new way, asking parents different questions about their kids and any diagnosis of autism. They say it's probably the most accurate estimate yet, and stress that it almost certainly doesn't show some big increase in autism actually occurring among children.

Instead, they say, it's clear that doctors are changing the way they diagnose autism and parents are far more likely than in years past to seek a diagnosis for their kids.

"One in 45 is what we think is the most accurate parental report of autism to date. I think within this report we found that the way that we ask the parents about autism spectrum disorder can have an impact on the way the parents respond to the question," said Benjamin Zablotsky, an epidemiologist at the National Center for Health Statistics who helped lead the study.

We feel we are asking the question in a better way than before."

It's a hot topic in the U.S., with many parents and advocacy groups saying something must be happening to make so many kids develop autism. Other experts say it's almost certainly more likely that the condition is being recognized and diagnosed more often.

"We feel we are asking the question in a better way than before."

Zablotsky's team got their data from detailed surveys of 35,000 U.S. households. Parents of children aged 3 to 17 were asked specifically if their child had ever received a diagnosis of autism.

"The estimated prevalence of ASD (autism spectrum disorder) based on 2014 data was 2.24 percent, a significant increase from the estimated annualized prevalence of 1.25 percent based on 2011-2013 data," they wrote in their report released Friday.

"In contrast, the prevalence of other developmental disorders declined significantly from 4.84 percent based on 2011-2013 data to 3.57 percent based on 2014 data," they wrote.

"It's a high number and it's a scary number," said Michael Rosanoff, director of public health for the advocacy group Autism Speaks. "It's another piece of evidence suggesting we are under-reporting the prevalence of autism in the U.S."

Earlier questionnaires were a bit more complicated, with parents being asked if a child had ever been diagnosed with a developmental disorder, including autism. This may have been confusing, Zablotsky said.

"In previous years, it is likely that some parents of children diagnosed with autism spectrum disorder reported this developmental disability as other developmental disorders instead of, or in addition to, ASD," his team wrote.

Hard to define

Dr. Lisa Shulman, an autism specialist in the pediatrics department of the Albert Einstein College of Medicine, said it's often hard to clearly define autism to parents, and difficult for people to remember what diagnosis a child got.

"That is definitely the take-home message. It's hard to get a number," Shulman told NBC News.

Autism spectrum disorder refers to a big range of conditions, from the relatively mild symptoms of Asperger's to severe and profound intellectual deficits and an inability to communicate with others. Symptoms often overlap with other disorders such as attention deficit/hyperactivity disorder, cerebral palsy or various learning disorders.

The Centers for Disease Control and Prevention has been studying how common autism is for years now, since parents began worrying that perhaps something kids were exposed to — notably vaccines — might cause autism. Many studies have shown vaccines do not cause autism, and CDC has promised to try to find out what is causing it.

Every year, the number of cases diagnosed goes up. In the latest study before this one, CDC found a 30 percent spike in autism diagnoses among 8-year-olds between 2008 and 2010 to one in 68 children.

There are certainly genetic links, and some evidence that infections in pregnancy, such as influenza, might play a role, as well.

Laurie Alderman, a research scientist in George Washington University's Department of Special Education and former coordinator of autism services for Arlington County Public Schools in Virginia, says she doesn't think there's much more autism now than there was 30 or 40 years ago.

"These kids have always been there," Alderman told NBC News.

"I started teaching in 1979 and I have always had students who were a little quirky, a little odd, a little rigid."

Some kids were just kept in classrooms with everyone else. Others were classified as disabled. "These kids were in special education because they had 'mental retardation' or a physical disability, a learning disability, ADHD," she said.

Money follows diagnosis

Now autism is something commonly talked about, and there's growing evidence that kids can be helped.

"There are so many more professionals who can diagnose autism now," Alderman added. "It used to be when I started out and parents were asking about this you had to go to major medical center to get an autism diagnosis."

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism."

Children are also diagnosed at much younger ages than before, she noted.

And parents now know they can get services for their children with an autism diagnosis, all the experts agree.

"Money follows diagnosis. And there's a lot more money that's attached to a diagnosis of autism than there would be to a diagnosis of developmental language disorder or.... a learning disability to give you an example," said Dr. Max Wiznitzer, a child neurologist at Rainbow Babies & Children's Hospital in Cleveland. "And with more money, you can provide more services."

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How changing a questionnaire nearly doubled America's autism rate
November 13, 2015
Bloomberg Business

BY: John Tozzi
http://www.bloomberg.com/news/articles/2015-11-13/autism-rate-nearly-doubles-on-paper-after-a-survey-is-changed
Adding a more detailed question led more parents to report that their children had the diagnosis. About 1.25 percent of kids in the U.S. had a diagnosis of autism spectrum disorder from 2011 to 2013, according to the National Health Interview Survey. In 2014, it was 2.24 percent -- a colossal move, in statistical terms. That doesn't mean an extra 600,000 kids developed autism last year. The difference is explained by a change in the order of questions and other adjustments in the 2014 survey, the Centers for Disease Control reports today. The statistical hiccup is a lesson in the difficulty of measuring health in the general population. It's especially hard for conditions like autism -- a developmental disorder marked by difficulty in communicating and socializing -- that have had shifting diagnostic criteria. The federal government has been using the National Health Interview Survey, intended to be nationally representative of U.S. households, since 1957. Surveyors visit people at home and ask questions about household members of all ages. Parents answer for their children. In recent years, the survey has questioned families of about 11,000 kids age 3 to 17 on autism and other developmental delays. In 2011 through 2013, surveyors asked parents whether doctors had ever told them their child had an intellectual disability, and then asked about any other developmental delays. Then they provided a list of 10 conditions, including autism alongside diabetes, arthritis, and others, and asked the parents to tell them which, if any, their child had. In 2014, rather than including autism on a list of other conditions, the survey inserted a question specifically about autism spectrum disorders. It came after the question about intellectual disabilities and before the question about other developmental delays. That apparently led some parents who might have previously chosen "other developmental delay" to indicate an autism diagnosis instead.There were big swings in the responses about autism and other developmental delays after the survey changed. But when researchers looked at the total number of people who responded yes to either question, there was very little difference: The more direct autism question "is likely to receive more attention and more thoughtful responses," authors from the CDC's National Center for Health Statistics write. So it's probably capturing diagnoses the earlier surveys missed. "True year-to-year changes of the magnitude observed are unusual," the authors note, "and require abrupt or dramatic changes in the risk factors acting on the population."

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You won't guess why U.S. autism prevalence is now 1 in 45
November 13, 2015
Forbes

BY: Emily Willingham
http://www.forbes.com/sites/emilywillingham/2015/11/13/you-wont-guess-why-u-s-autism-prevalence-is-now-1-in-45/
Is it vaccines? Air pollution? Infections?

Nope. The reason that the latest numbers for autism prevalence among US children have climbed traces largely to a simple change in how interviewers asked a question.

The US Centers for Disease Control and Prevention last conducted the National Health Interview Survey (NHIS) for the years 2011 through 2013. The 2014 survey, though, included a tweak, and that tweak is the reason that autism prevalence climbed from 1.25% to 2.24% in 2014. Not even the most die-hard causation theorist could argue that in a single year or handful of years, something environmental, like vaccines, caused a near-doubling of autism prevalence in children ages 3 to 17 years.

So what underlies the increase?

For the 2011-2013 survey, parents answered a series of three questions. The first asked if their child had intellectual disability. The second asked if their child had any developmental delay. And the third question listed several conditions, from Down syndrome to sickle cell anemia to autism spectrum disorder (ASD), and parents were asked if their child had been diagnosed with any of them.

But 2014 brought some tweaks, and those tweaks made a difference. The intellectual disability question came first again. But the second question directly asked parents if their child had an ASD diagnosis. The third question then asked about any other developmental delay. More than 10,000 parents are interviewed in each year of this survey.

The simple change to emphasize the autism question resulted in the near doubling of prevalence from 2011–2013 to 2014. Underscoring that this increase reflects a shift in how parents responded to the questions, the prevalence of 'other developmental disorders' dropped in that same time period from 4.84% in 2011-2013 to 3.57% in 2014. Intellectual disability prevalence remained pretty much the same in the two periods, and the collective prevalence for all three conditions (intellectual disability, ASD, and other developmental disorders) also remained stable.

What a difference a question can make. But that might not have been the sole influence on the results.

Paul Lipkin, director of medical informatics at the Kennedy Krieger Institute and of the institute's Interactive Autism Network, sees the reordering and rewording of the questions as one factor. The changes place a "higher priority on identifying autism," he said in an email, but "at the same time, we know that professionals, parents, and the public also are more attuned to ASD and its identification at all ages."

These latest values bring the results of three national surveys of autism prevalence into alignment. In addition to the NHIS, the US also identifies autism prevalence values from the Autism and Developmental Disabilities Monitoring Network (ADDM) and the National Survey of Children's Health (NSCH). The most recent results from the NSCH put autism prevalence at 1 in 50 children. This latest NHIS prevalence of 1 in 45 converges on that finding, and the agreement among the studies strengthens their conclusions.

Lipkin noted that the advantages of the NHIS study are that it doesn't involve preselecting households for autism or other developmental conditions and samples across ages, unlike ADDM, which focuses on 8-year-olds.

The 2.24% prevalence also is remarkably close to the 2.64% reported in a thorough investigation of autism prevalence in the South Korean population. Lipkin sees that similarity as pointing to the

universality of autism. “This is not a function of professional practice, cultural differences in parenting, or differing parental perspectives on their children,” he said.

The report also shows some stabilizing of previous disparities and a closing gap between girls and boys diagnosed with autism. Earlier surveys and some research have suggested that autism is four or five times more common in boys than in girls, but the NHIS survey has it as just under 3 times more common in boys (3.29 vs 1.15 in girls).

Some of the gaps among ethnicities also appear to be narrowing: ASD prevalence among non-Hispanic white children was 2.55 in the NHIS survey and 2.21 among non-Hispanic blacks, but still lower among Hispanic children at 1.49. Prevalence also is lower among uninsured families, possibly reflecting an access issue.

One final result to highlight from this survey: The results are similar for age groups, at 2.34 for children ages 3-10 and 2.13 for children ages 11-17. That similarity also suggests some stability across the years in the true prevalence of this condition, whether a child was born in 1998 or in the 21st century.

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Autism rate doubles in US to one in 45 kids: survey
November 13, 2015
Agence France Presse

BY: Franck Fife
http://www.afp.com/en/news/autism-rate-doubles-us-one-45-kids-survey
Autism affects one in 45 children in the United States, almost twice the rate from a few years ago, said a survey Friday that uses a new approach to assess the frequency of the developmental disorder.

The latest figures may reflect a more accurate picture of autism spectrum disorder, said the report by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, and so does not necessarily mean that there is a ballooning autism epidemic.

In fact, the study found that while autism spectrum diagnoses are more frequent than in the past, the overall number of people affected by neurodevelopmental problems has not risen, but has remained steady over time.

"What we call an autism spectrum disorder now is a much wider group of symptoms than what we called autism in the past so I think that captures a larger number of children that might have received other diagnoses in the past," said Katie Walton, an autism researcher who was not involved with the CDC survey.

"There have been some significant changes in the way that they are asking the questions," added Walton, a psychologist at the Ohio State University's Nisonger Center.

The report found that in 2014, one in 45 children had autism spectrum disorder, or 2.24 percent.

When the survey was given in 2011-2013, one in 80 children was diagnosed with ASD (1.25 percent).

The prevalence of autism in the United States was just one in 5,000 in 1975, and has been rising steadily in recent years.

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people. It is believed to be influenced by genetic and environmental factors, though scientists do not fully understand all its causes.

There is no known cure, but early intervention in toddlers as young as two can sometimes help.

There is no known cure for autism, but early intervention can be beneficial

Officials changed the order of the questions posed in the latest survey, completed by more than 11,000 parents, a process that may have resulted in more of them acknowledging a diagnosis of ASD.

"The question wording was expanded to include more specific details on what constituted an autism spectrum disorder," said the report.

Since the United States does not maintain national health registries, telephone surveys are among the ways that experts assess the rate of autism.

School and medical records have also been used to project a nationwide autism rate of one in 68 children, according to another CDC report issued in 2014.

- 'No epidemic' -

Some experts agree that these surveys do not suggest there is a worsening epidemic of autism in the United States.

A study out earlier this year led by Santhosh Girirajan, assistant professor of biochemistry and molecular biology and of anthropology at Penn State, found that the rising rate of autism seen in recent years resulted from reclassifying individuals with related neurological disorders.

His study analyzed 11 years of special-education enrollment data on an average of 6.2 million children per year, and found "no overall increase in the number of students enrolled in special education."

Autism spectrum disorder is a developmental disability that may cause a person to have difficulty behaving, learning, communicating and interacting with people

Asked for comment on Friday's figures, he told AFP that the CDC's latest approach is an improvement.

"When people say (there is an) epidemic of autism, I am not really sure," he said.

"It is true that they are identifying more individuals with autism because autism is occurring with other disorders," he added.

Better diagnoses -- and improved strategies for estimating prevalence -- may be useful to parents who want to get improved treatment for their children at an early age, added Walton.

"I think people should understand that autism is a relatively common condition at this point and if you are concerned about your child... there are an increasing number of services out there," she said.

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1 in 45 U.S. kids has an autism spectrum disorder
November 13, 2015
LiveScience.com

BY: Cari Nierenberg
http://www.livescience.com/52790-autism-spectrum-disorder-prevalence-us-2014.html

About 1 in 45 children in the United States has an autism spectrum disorder, according to a new government estimate of the condition's prevalence in 2014.

This new report is based on data collected during the yearly National Health Interview Survey, from interviews of parents about their children, and is the first report of the prevalence of autism in the U.S. to include data from the years 2011 to 2014, according to the researchers from the Centers for Disease Control and Prevention (CDC).

Although the new estimate looks like a significant increase from the CDC's previous estimate — which put the autism spectrum disorder rate at 1 in 68 children — the previous estimate was made using data from a different CDC survey, called the Autism and Developmental Disabilities Monitoring Network, which gathers information from children's medical records. This 1-in-68 estimate was reported in 2014, but was based on data collected during 2010.

None of the interview surveys and monitoring methods that report increasing prevalence rates of autism in the U.S. looked at why these numbers seem to be rising. But one reason could be that awareness of the condition has increased among both parents and health care providers, which has

likely led to more children with the condition being identified, said Robert Fitzgerald, an epidemiologist in psychiatry at the Washington University School of Medicine in St. Louis, who was not involved in the research.

For example, in the past, some kids now considered to have an autism spectrum disorder (ASD) may have been labeled as having an "intellectual disability," he said. There have also been recent changes in the diagnostic criteria and symptoms used to describe ASD.

Another reason is that the stigma of having autism has decreased, Fitzgerald said. Previously, even doctors may not have wanted to give kids the label of "autism," leading children's medical records to reflect an underdiagnosis of actual cases. Now, there has been an increase in services and support for children who have ASD, so this may have resulted in a different mind-set, he said.

For the new report, nearly 12,000 parents of children ages 3 to 17 from across the U.S. sat down with researchers for face-to-face interviews in 2014, and about 11,000 parents were interviewed each year from 2011 to 2013.

The rate of autism in 2014 (1 in 45) was higher than the rate researchers found in 2011 to 2013, which was 1 in 80 children with ASD.

However, in 2014, the researchers changed the way they collected the data, said the lead author of the new report, Benjamin Zablotsky, an epidemiologist in the Division of Health Interview Statistics at the National Center for Health Statistics in Hyattsville, Maryland.

Therefore, much of what seems like an increase in ASD between 2011 and 2014 was actually a function of the way the interviewers asked the questions, Zablotsky said.

In 2014, the researchers first asked parents whether a doctor or health professional ever told them that their child had an intellectual disability, also known as mental retardation. The second question was a stand-alone question about ASD: Parents were asked whether a health professional ever told them their child had autism, Asperger's disorder, pervasive developmental disorder or autism spectrum disorder. The final question asked whether a health professional had ever told parents their child had any other developmental delay.

When interviewers questioned parents in 2011 through 2013, they asked the same first question about intellectual disability, but then their second question asked about other developmental delays. In the third question, parents were asked to look at a list of 10 conditions, including autism/ASD, and to indicate whether a health professional ever told them their child had one of these conditions.

This approach — of including autism in a checklist instead of asking a specific question about it — might have resulted in the name of the condition sometimes getting lost in the shuffle, Zablotsky said.

The revised approach was implemented in 2014 to better align with the wording used in other national surveys that estimate the prevalence of autism, and to include the specific terms that parents may have heard health care professionals use when making a diagnosis, Zablotsky said.

Also, putting the autism question second, before the question about other developmental delays, resulted in the 2014 data showing a higher prevalence rate for ASD, and a lower prevalence rate for other developmental delays. The opposite seemed to occur in 2011 to 2013, when the questions were the other way around — those data showed a higher reported rate of children with developmental delays, and a lower rate of ASD.

Increased prevalence

Fitzgerald agreed that what looks like an increase in autism's prevalence in 2014 was probably due to the way the interviewers asked the questions on the survey, rather than a real change in ASD prevalence within the population.

To see that big of a change in prevalence over a four-year period — from 1 in 80, to 1 in 45 — researchers would also need to be seeing a dramatic change in risk factors for autism in the population, Fitzgerald said.

How parents understand and interpret the questions they are asked during an interview and how well they can accurately recall their child's diagnosis influence the responses they give and affects the results, Fitzgerald told Live Science.

The 2014 results were probably a more accurate measurement of the true prevalence of autism because they produced estimates similar to those of other recent survey methods, he said. The 2011-2013 data identified fewer cases of autism because of the way parents were answering the questions, he said.

The big question is whether the U.S. will continue to see an increase in cases of autism, Fitzgerald said.

Results from the last 10 years have been finding increases in prevalence rates, and they have not yet shown a leveling off, he said.

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New estimate shows more American children with autism
November 13, 2015
WSB TV-2 (Atlanta)

BY: Associated Press contributed
http://www.wsbtv.com/news/news/local/new-estimate-shows-more-american-children-autism/npMm9/
A new government estimate shows autism is more common— 1 in 45 U.S. children — but other federal calculations say the developmental disorder is less common.

The latest figure released Friday is one of three estimates that the Centers for Disease Control and Prevention gives for autism based on different surveys; the most rigorous one gives a lower estimate of 1 in 68 children.

The new number is from a survey of parents of 13,000 children, who were asked last year if their child were ever diagnosed with autism or a related disorder. The lower CDC estimate is from researchers checking health and school records for more than 47,000 children.

The 1 in 68 will still be treated as the best estimate, said Michael Rosanoff, director of public health research for the advocacy group Autism Speaks.

But the new number supports a belief that 1 in 68 is an underestimate, he added.

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CDC survey finds autism on the rise
November 13, 2015
Disability Scoop
BY:Michelle Diament

Autism may affect as many as 1 in 45 American children, according to a new government survey.

In a report released Friday, the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics said that as of 2014, some 2.24 percent of American kids had received a diagnosis on the spectrum.

The figures come from the National Health Interview Survey, which last year asked 11,000 parents of kids ages 3 to 17 across the country if they were ever told by a doctor or health professional that their child had autism, intellectual disability or other developmental disabilities.

By comparison, similar data from 2011 to 2013 found an autism prevalence rate of 1.25 percent, the report indicated.

Despite a large uptick in reported autism prevalence, however, researchers with the National Center for Health Statistics said the variation is likely due in part to changes in the way the survey asked about autism.

"In previous years, it is likely that some parents of children diagnosed with ASD reported this developmental disability as other DD instead of, or in addition to, ASD," they wrote.

The survey is also just one of a handful of methods the government uses to measure autism prevalence. Findings from a different study — which regularly assesses medical and educational records of 8-year-olds in various pockets of the country — are still considered the CDC's official estimate. That study most recently concluded that 1 in 68 American children have autism.

Aside from autism, the 2014 survey found that the prevalence of intellectual disability remained largely unchanged at 1.1 percent. However, the number of children with other developmental disabilities declined sharply to 3.57 percent in 2014, down from 4.84 percent in the 2011 to 2013 data, the report said.

When combined, researchers said the prevalence of children with all developmental disabilities "did not differ significantly" in the 2014 survey compared to the previous years.

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Fri, 29 Aug 2014 12:34:55 -0400
To: Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: DeStefano Follow Ups

Ha – thanks, Frank. Let me take a look.

-Angela

From: Destefano, Frank (CDC/OID/NCEZID)
Sent: Friday, August 29, 2014 12:21 PM
To: Fisher, Angela H. (CDC/OID/NCEZID) (CTR); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: DeStefano Follow Ups

These responses seem ok. I personally would (b)(5)

(b)(5)

Thanks,
Frank

From: Fisher, Angela H. (CDC/OID/NCEZID) (CTR)
Sent: Friday, August 29, 2014 10:16 AM
To: Destefano, Frank (CDC/OID/NCEZID); Gonzalez, Belsie (CDC/OD/OADC)
Cc: Coffin, Nicole (CDC/OID/NCEZID); Brower, Melissa (CDC/OID/NCEZID); Weinbaum, Cindy (CDC/OID/NCEZID)
Subject: RE: DeStefano Follow Ups

Frank and Belsie:

Per Sharyl Attkinsson's f/u request, pasted below please find our suggested responses. These have been developed in partnership with Cindy and Coleen. Would you mind reviewing quickly and letting me know if you have any edits? I'd like to circle back with her this morning if possible. Many, many thanks!

Best,

-Angela

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ahfisher@cdc.gov
Telework: Tuesdays and Fridays

From: Sharyl Attkisson [mailto:(b)(6)]
Sent: Wednesday, August 27, 2014 8:26 PM
To: Brower, Melissa (CDC/OID/NCEZID)
Subject: DeStefano Follow Ups

Melissa, can you ask Dr. DeStefano to answer these follow ups. If it's easier for him to do it on the phone, I'm available. Thank you.

What constitutes/defines something as a "causal" relationship? (I was thinking about smoking and lung cancer. Most people who smoke will never get lung cancer. Those who do must have some predisposition (genetic or other exposures). Therefore, would CDC say smoking is not "causal," but more "secondary"—as I described yesterday—because it's a "trigger"?)

(b)(5)

(b)(5)

(b)(5)

Was the original statistical increase only in African American boys or in a broader group as well? Was it more than a three-fold increase for black boys, as Thompson has stated?

(b)(5)

(b)(5)

Should the decision to change the analysis plan, and the reasons behind it, have been included in the paper? (if not, why?)

(b)(5)

In general, do African American boys have a greater incidence of autism than other populations? If so, can you characterize?

(b)(5)

SharylAttkisson.com
Investigative Journalist
"Stonewalled" (Harper Collins Nov. 2014)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 7 Oct 2014 19:13:47 +0000
To: Ikeda, Robin (CDC/ONDIEH/OD)
Subject: RE: EOY

Are you coming to the meeting tomorrow with Harold on the MMR--autism analysis? I can sign it then.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

-----Original Message-----
From: Ikeda, Robin (CDC/ONDIEH/OD)
Sent: Tuesday, October 07, 2014 3:08 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: EOY

I have you end of year evaluation for review/signature. I can drop off tomorrow or am open to other suggestions. Thanks.

From: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 12 Nov 2014 21:15:24 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Re: Erroneous Online Autism Spectrum Disorder Quiz Answer

Hi Coleen. Yes I will get with the program about this tomorrow. Thanks.
Sent from my BlackBerry 10 smartphone on the Verizon Wireless 4G LTE network.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, November 12, 2014 1:25 PM
To: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Cc: Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: Fwd: Erroneous Online Autism Spectrum Disorder Quiz Answer

Hi Karen: could you address the issue below with the program? Thx

Sent from my iPad

Begin forwarded message:

From: "Arias, Ileana (CDC/OD)" <iaa4@cdc.gov>
Date: November 12, 2014 at 12:49:24 PM EST
To: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Cc: "Ikeda, Robin (CDC/ONDIEH/OD)" <rmi0@cdc.gov>, "Bonzo, Sandra E. (CDC/ONDIEH/OD)" <seb2@cdc.gov>
Subject: FW: Erroneous Online Autism Spectrum Disorder Quiz Answer

FYI and thanks to your staff for quick action. (b)(5)

(b)(5)

From: Arias, Ileana (CDC/OD)
Sent: Wednesday, November 12, 2014 12:31 PM
To: 'tim morgan'
Subject: RE: Erroneous Online Autism Spectrum Disorder Quiz Answer

Tim,

Thanks for your email. You are absolutely correct about the inaccuracy and program staff have made the correction: http://www.cdc.gov/ncbddd/autism/quiz.html

Ileana

From: tim morgan [mailto:(b)(6)@gmail.com]
Sent: Wednesday, November 12, 2014 12:06 AM
To: Frieden, Thomas (Tom) (CDC/OD); Arias, Ileana (CDC/OD)
Subject: Erroneous Online Autism Spectrum Disorder Quiz Answer

Dear Dr. Frieden and Dr. Arias,

I would like to bring your attention to question 8 on the CDC's online quiz, "How much do you know about ASD? Test your knowledge...", in which the "Correct" popup window and explanation is not linked to the appropriate answer. I think this is an excellent resource for the public; however, this mistake may result in unwanted confusion and a misunderstanding of an important aspect of ASD. I hope this e-mail makes its way to the appropriate person and the correction be made.

Sincerely,

Tim Morgan

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 13 Nov 2014 21:34:19 +0000
To: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Cc: Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: Re: Erroneous Online Autism Spectrum Disorder Quiz Answer

Thanks. Works for me.

Sent from my iPad

On Nov 13, 2014, at 3:27 PM, Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov> wrote:

Hi Coleen. (b)(5)
(b)(5)
(b)(5) Sharon Meek is taking care of this but says it will likely be tomorrow before she can locate all of the links to the quiz and have them archived, which will pull it down from the website. Please let me know if you need me to do anything further.

Best,
Karen

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, November 12, 2014 1:25 PM
To: Hunter, Karen (CDC/ONDIEH/NCBDDD)
Cc: Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD)
Subject: Fwd: Erroneous Online Autism Spectrum Disorder Quiz Answer

Hi Karen: could you address the issue below with the program? Thx

Sent from my iPad

Begin forwarded message:

From: "Arias, Ileana (CDC/OD)" <iaa4@cdc.gov>
Date: November 12, 2014 at 12:49:24 PM EST
To: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Cc: "Ikeda, Robin (CDC/ONDIEH/OD)" <rmi0@cdc.gov>, "Bonzo, Sandra E. (CDC/ONDIEH/OD)" <seb2@cdc.gov>
Subject: FW: Erroneous Online Autism Spectrum Disorder Quiz Answer

FYI and thanks to your staff for quick action. (b)(5)

(b)(5)

From: Arias, Ileana (CDC/OD)
Sent: Wednesday, November 12, 2014 12:31 PM
To: 'tim morgan'
Subject: RE: Erroneous Online Autism Spectrum Disorder Quiz Answer

Tim,

Thanks for your email. You are absolutely correct about the inaccuracy and program staff have made the correction: http://www.cdc.gov/ncbddd/autism/quiz.html

Ileana

From: tim morgan [mailto:(b)(6)@gmail.com]
Sent: Wednesday, November 12, 2014 12:06 AM
To: Frieden, Thomas (Tom) (CDC/OD); Arias, Ileana (CDC/OD)
Subject: Erroneous Online Autism Spectrum Disorder Quiz Answer

Dear Dr. Frieden and Dr. Arias,

I would like to bring your attention to question 8 on the CDC's online quiz, "How much do you know about ASD? Test your knowledge...", in which the "Correct" popup window and explanation is not linked to the appropriate answer. I think this is an excellent resource for the public; however, this mistake may result in unwanted confusion and a misunderstanding of an important aspect of ASD. I hope this e-mail makes its way to the appropriate person and the correction be made.

Sincerely,

Tim Morgan

From: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Sent: Thu, 30 Oct 2014 09:18:40 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Federal Benefits Open Season Fairs; NCBDDD Request for Objective Reviewers; Public Health Grand Rounds

Will do. I've asked the other ONDIEH Centers if they could help with staffing the review.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, October 30, 2014 9:11 AM
To: Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)
Subject: FW: Federal Benefits Open Season Fairs; NCBDDD Request for Objective Reviewers; Public Health Grand Rounds

Pls see below. It looks like Nicole et al are still to recruit obj reviewers. We can help them find some good people. Could you reach out to Nicole F to get the latest? I would be happy to reach out to various Div Dir that I know

Coleen A. Boyle, PhD, MS hyg
Director
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Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: CDC Today
Sent: Thursday, October 30, 2014 8:00 AM
To: CDC Today
Subject: Federal Benefits Open Season Fairs; NCBDDD Request for Objective Reviewers; Public Health Grand Rounds

Click here to view today's announcements filtered by your custom preferences.

TODAY'S ANNOUNCEMENT TITLES

- ITSO Weekly CDCMail Maintenance Outage Tonight at 10:00 pm ET
- 2014 CDC Health Days – Flu Shot Open Houses (flu shots in select locations only, all other services available at all Health Days. See flyer for details),
- Attention, CDC Project Officers! TASII Learning Opportunity—Training Services for CDC Programs and Partners
- ATTENTION: REVIEWERS NEEDED IMMEDIATELY NCBDDD Request for Objective Reviewers under FOA #CDC-RFA-DD15-1501 Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the ADDM Network
- Federal Employees' Compensation Act Training for Supervisors
- Fire Alarm Testing Bldg 101 and 102 at Chamblee Campus
- Flu Shot Cancellation: for an updated schedule, please visit CDC's Wellness webpage http://intranet.cdc.gov/wellness
- Garden Market at Roybal today 10:30 - 3:30
- Grocery Store Tours: Smart Shopping for Diabetes
- PHIN Partner Call - November 05, 2014
- REMINDER: CDC/ATSDR 2nd Annual Veterans Day Commemoration, Thursday, NOVEMBER 6, 2014
- Road Construction Along the Clifton Corridor
- Roybal Campus - Building 16 - Parking Deck Lane Closure - Wednesday, November 5, 2014
- Save the Date: Public Health Grand Rounds – November 2014
- SAVE THE DATES - Federal Benefits Open Season Fairs: November 12-13 and December 1!
- Tuesday Morning Seminar (TMS) - November 4
- Wellness Blog: What's cool about cholesterol screening?

FEATURED ANNOUNCEMENT(S)

ATTENTION: REVIEWERS NEEDED IMMEDIATELY NCBDDD Request for Objective Reviewers under FOA #CDC-RFA-DD15-1501 Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the ADDM Network - The Developmental Disabilities Branch, Division of Birth Defects and Developmental Disabilities, NCBDDD, is seeking volunteers to serve as reviewers on an objective review panel to review applications received in response to Funding Opportunity Announcement (FOA), DD15-1501: Enhancing Public Health Surveillance of Autism Spectrum Disorder and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network. The review panel will be conducted 11/5/14.

Save the Date: Public Health Grand Rounds – November 2014 - Please plan to attend the next session of Public Health Grand Rounds, "Unusual Transplant-associated Infections: Just How Unusual?," which will be held on November 18, at 1 p.m. (EST).

SAVE THE DATES - Federal Benefits Open Season Fairs: November 12-13 and December 1! - HRO is pleased to announce that it will hold three Federal Benefits Open Season Fairs on November 12 -13 and December 1, 2014. View the full announcement for details.

General Announcements

ITSO Weekly CDCMail Maintenance Outage Tonight at 10:00 pm ET - CDCMail service will be interrupted for several brief periods tonight, Thursday night, beginning at 10:00 p.m. ET during regular scheduled maintenance; which will occur each week at this time. The impact of this outage depends on how you access e-mail. See below for specific impact.

2014 CDC Health Days – Flu Shot Open Houses (flu shots in select locations only, all other services available at all Health Days. See flyer for details), - Due to ongoing and increasing efforts to support the Ebola response, flu shots have been CANCELLED FOR THE FOLLOWING DATES ONLY: 11/4 Century Center; 11/7 Corporate Square; 11/12 UOP/Sanford Building ; 12/3 Chamblee; 12/11 Roybal. CDC Health Day screenings WILL still occur on these dates for biometric screenings and Personal Wellness Profiles (NEW!). No appointments for flu shots will be offered through the CDC clinics. Please take advantage of one of the seven remaining CDC Health Days.

Attention, CDC Project Officers! TASII Learning Opportunity—Training Services for CDC Programs and Partners - The Division of Scientific Education and Professional Development's Education and Training Services Branch improves the quality of, and increases access to, high quality accredited public health training. The latest session, "Training Services for CDC Programs and Partners," will describe the services available to your program (many of which are also available to your grantees). Register today! - **Add to my Outlook Calendar**

Federal Employees' Compensation Act Training for Supervisors - The Human Resources Office, Workforce Relations Office will present Federal Employees' Compensation Act Training for Supervisors. This training session is available to supervisors only and covers the rules, processes, and procedures related to the Workers' Compensation Program. Additional training classes will be offered for supervisors who are not able to attend this session.

Fire Alarm Testing Bldg 101 and 102 at Chamblee Campus - The Asset Management Services Office will test the fire alarm system for Building 101 and 102 November 3-5 from 6:00 p.m. to 10:00 p.m. The alarm will sound. If there is an actual emergency, an announcement will be made to evacuate the building. We regret the inconvenience and appreciate your patience. Please direct questions to Herbert Smith at 404-639-0145.

Flu Shot Cancellation: for an updated schedule, please visit CDC's Wellness webpage http://intranet.cdc.gov/wellness - Due to ongoing and increasing efforts to support the Ebola response, flu shots have been CANCELLED for the following dates: 11/4 Century Center; 11/7 Corporate Square; 11/12 UOP/Sanford Building ; 12/3 Chamblee; 12/11 Roybal. Health Day screenings WILL still occur on these dates. No appointments for flu shots will be offered through the CDC clinics.Please take advantage of one of the seven remaining CDC Health Days.As always, flu shots are readily available through your doctor or local pharmacy

Garden Market at Roybal today 10:30 - 3:30 - Check out the Garden Market newsletter! Inside you can find the Garden Market schedule, the weekly specials, and the recipe of the week. See page two to stay up to date on current Worklife Wellness events!

Grocery Store Tours: Smart Shopping for Diabetes - November is Diabetes Awareness Month! Whether you have diabetes or are trying to prevent it, you'll appreciate this tour designed to help you make better food choices. Participants will learn how to read food labels, how to count carbohydrates, and the impact of different nutrients on blood sugar.

PHIN Partner Call - November 05, 2014 - The purpose of the PHIN Partner Call is to maintain communication and provide an opportunity to share information with our internal and external partners on PHIN and other related activities.

REMINDER: CDC/ATSDR 2nd Annual Veterans Day Commemoration, Thursday, NOVEMBER 6, 2014 - You are cordially invited to join us in saluting our veteran workforce at CDC and ATSDR, and all veterans, for their commitment, sacrifice, and service.

Road Construction Along the Clifton Corridor - Road work continues along the Clifton Corridor adjacent to Emory Point throughout the months of November and December.

Roybal Campus - Building 16 - Parking Deck Lane Closure - Wednesday, November 5, 2014 - On Wednesday, November 5, 2014, beginning at 9:00 am until 4:00 pm, the Asset Management Services Office will close traffic lanes on the south side of the Building 16 parking deck to locate utilities.

Tuesday Morning Seminar (TMS) - November 4 - Please join us for this weekly seminar presented by the Epidemic Intelligence Service (EIS) program. This week's presentation, "First Use of a Novel Serogroup B Meningococcal Vaccine in the U.S. in Response to a University Outbreak—New Jersey, 2013," will be delivered by EIS officer Lucy McNamara, PhD, MS (NCIRD) with discussant Robin Izzo, MS (Princeton University). Date of event:

November 4, 2014. - **Add to my Outlook Calendar** 

Wellness Blog: What's cool about cholesterol screening? - Check out the latest Worklife Wellness blog post to learn how to get your cholesterol checked at work, and why it matters

if your cholesterol is
high.http://blogs.inside.cdc.gov/livingwell/2014/10/28/cholesterol-screening/

If you have questions concerning access, or experience technical problems accessing these announcements, please contact **Larry Ponder (lbp5@cdc.gov)** for assistance.

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thu, 4 Dec 2014 10:22:34 -0500
To: Arroyo, Sam (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Working now – thanks!

From: Arroyo, Sam (CDC/ONDIEH/NCBDDD) (CTR)
Sent: Wednesday, December 03, 2014 3:11 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Cc: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

I see. Just refresh your browser and try again.

v/r,

Sam Arroyo
W#: (4) 498-1361
Khq5@cdc.gov

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Wednesday, December 03, 2014 2:21 PM
To: Arroyo, Sam (CDC/ONDIEH/NCBDDD) (CTR); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Thanks so much! I can open all of the folders but when I do it says there are no documents to share.

-----Original Message-----
From: Arroyo, Sam (CDC/ONDIEH/NCBDDD) (CTR)
Sent: Wednesday, December 03, 2014 02:01 PM Eastern Standard Time
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

Hi Coleen,

Not a problem!

Kathleen,

What are you getting (if something) will trying to access the folder?

v/r,

Sam Arroyo
W#: (4) 498-1361
Khq5@cdc.gov

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, December 03, 2014 1:57 PM
To: Arroyo, Sam (CDC/ONDIEH/NCBDDD) (CTR)
Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: FW: Files

Hi Sam: Kathleen Ethier is unable to access the SharePoint inquiry folder that you set up for me (you gave her access to read the files.) Could you contact Kathleen to help with her gaining access? Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Wednesday, December 03, 2014 9:39 AM

To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Thanks. I can see all of the subfolders but when I open them it says there are no shared documents. If you could have Sam drop me an email, that would be great. I don't use Sharepoint very often so I may just be doing something wrong.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, December 03, 2014 9:02 AM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I cked the link and it worked perfectly for me. Try clicking on the link embedded below. That should bring you to a SharePoint directory called "Inquiry" with a page showing a folder called "2004 MMR autism paper". If you click on the folder it will show all the files (some in subfolders) that I have.

If you can assess it, I will ask our SharePoint expert – Sam Arroyo reach out to you. Also, I made a CD of the files – that might be easiest, but I thought with the SharePoint dir you could easily share with others.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Tuesday, December 02, 2014 11:00 AM
To: Cono, Joanne (CDC/OD/OADS); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Hi Coleen,
Thanks for giving me access to the Sharepoint site. For some reason I'm not showing any documents in the folders. I'm not very good with Sharepoint, so I may be doing something wrong, but what should I be seeing in the folders?
Thanks,
Kathleen

From: Cono, Joanne (CDC/OD/OADS)
Sent: Tuesday, November 18, 2014 4:55 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

Wonderful, Coleen. Thanks for the info and records. I am cc'ing Kathleen who is cataloguing all materials, so it will be necessary for her to have access.

Best regards,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, November 18, 2014 12:45 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Files

Joanne: I put all the files out on a SharePoint directory that you should have access to. You can copy the files to your own directory (or we can give access to inquiry committee.)

Thanks, Coleen

(b)(6)

Sent: Thu, 16 May 2019 15:42:13 +0000
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I cked the link and it worked perfectly for me. Try clicking on the link embedded below. That should bring you to a SharePoint directory called "Inquiry" with a page showing a folder called "2004 MMR autism paper". If you click on the folder it will show all the files (some in subfolders) that I have.

If you can assess it, I will ask our SharePoint expert – Sam

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Tuesday, December 02, 2014 11:00 AM
To: Cono, Joanne (CDC/OD/OADS); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Hi Coleen,
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Thanks,
Kathleen

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Sent: Tuesday, November 18, 2014 4:55 PM
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Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

Wonderful, Coleen. Thanks for the info and records. I am cc'ing Kathleen who is cataloguing all materials, so it will be necessary for her to have access.

Best regards,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, November 18, 2014 12:45 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Files

Joanne: I put all the files out on a SharePoint directory that you should have access to. You can copy the files to your own directory (or we can give access to inquiry committee.)

Thanks, Coleen

(b)(6)

Sent: Thu, 16 May 2019 16:01:33 +0000
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

My programmer has submitted a request on Friday to establish a share drive and asked for the request to expediated. He just cked on this and we are still waiting. I will be out tomorrow but back on Wed. Hopefully we will have everything set up

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:26 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

That would be great – thanks!

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 19, 2015 5:20 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I don't know how to do that – but I can ask for help.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:19 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

If you just set up a very simple shared drive and give me access to it, that would be easiest. Thanks so much!

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 19, 2015 5:16 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I can put them on a floppy disk and drop off to you if that would be easiest – or copy them wherever you would like.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
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Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:13 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Hi Coleen,
I've been trying to work with the Sharepoint site where you've stored all of your documents and I think it isn't going to work for the panel's purposes. Is there any way you can have those files copied into a shared drive and just share it with me? That way I can copy them into the shared drive we're using for the investigation. Sorry for the additional burden.
Thanks,
Kathleen

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, December 03, 2014 9:02 AM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

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From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Tuesday, December 02, 2014 11:00 AM
To: Cono, Joanne (CDC/OD/OADS); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

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Kathleen

From: Cono, Joanne (CDC/OD/OADS)
Sent: Tuesday, November 18, 2014 4:55 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

Wonderful, Coleen. Thanks for the info and records. I am cc'ing Kathleen who is cataloguing all materials, so it will be necessary for her to have access.

Best regards,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, November 18, 2014 12:45 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Files

Joanne: I put all the files out on a SharePoint directory that you should have access to. You can copy the files to your own directory (or we can give access to inquiry committee.)

Thanks, Coleen

(b)(6)

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Mon, 23 Feb 2015 14:58:05 -0500
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Thanks, Coleen - sorry for the bother!

-----Original Message-----
From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Monday, February 23, 2015 01:49 PM Eastern Standard Time
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

My programmer has submitted a request on Friday to establish a share drive with a note to expedite. He just cked on this and we are still waiting. I will be out tomorrow but back on Wed. Hopefully we will have everything set up and to you on Wed. Sorry for the delay

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:26 PM

To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

That would be great – thanks!

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 19, 2015 5:20 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I don't know how to do that – but I can ask for help.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:19 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

If you just set up a very simple shared drive and give me access to it, that would be easiest. Thanks so much!

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 19, 2015 5:16 PM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I can put them on a floppy disk and drop off to you if that would be easiest – or copy them wherever you would like.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Thursday, February 19, 2015 5:13 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Hi Coleen,
I've been trying to work with the Sharepoint site where you've stored all of your documents and I think it isn't going to work for the panel's purposes. Is there any way you can have those files copied into a shared drive and just share it with me? That way I can copy them into the shared drive we're using for the investigation. Sorry for the additional burden.
Thanks,
Kathleen

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, December 03, 2014 9:02 AM
To: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

I cked the link and it worked perfectly for me. Try clicking on the link embedded below. That should bring you to a SharePoint directory called "Inquiry" with a page showing a folder called "2004 MMR autism paper". If you click on the folder it will show all the files (some in subfolders) that I have.

If you can assess it, I will ask our SharePoint expert – Sam Arroyo reach out to you. Also, I made a CD of the files – that might be easiest, but I thought with the SharePoint dir you could easily share with others.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Ethier, Kathleen (CDC/OD/PPEO)
Sent: Tuesday, December 02, 2014 11:00 AM
To: Cono, Joanne (CDC/OD/OADS); Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Files

Hi Coleen,
Thanks for giving me access to the Sharepoint site. For some reason I'm not showing any documents in the folders. I'm not very good with Sharepoint, so I may be doing something wrong, but what should I be seeing in the folders?
Thanks,
Kathleen

From: Cono, Joanne (CDC/OD/OADS)
Sent: Tuesday, November 18, 2014 4:55 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Cc: Ethier, Kathleen (CDC/OD/PPEO)
Subject: RE: Files

Wonderful, Coleen. Thanks for the info and records. I am cc'ing Kathleen who is cataloguing all materials, so it will be necessary for her to have access.

Best regards,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, November 18, 2014 12:45 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Files

Joanne: I put all the files out on a SharePoint directory that you should have access to. You can copy the files to your own directory (or we can give access to inquiry committee.)

Thanks, Coleen

(b)(6)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tue, 19 Aug 2014 21:18:34 +0000
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: RE: Focus Autism News Release _ CDC whistleblower

Sorry – didn't realize you received this already.

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Cl: (b)(6)
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, August 19, 2014 5:18 PM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: FW: Focus Autism News Release _ CDC whistleblower

FYI

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Cl: (b)(6)
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, August 19, 2014 9:57 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Lucido, Sal (CDC/ONDIEH/NCBDDD)
Cc: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Subject: FW: Focus Autism News Release _ CDC whistleblower

See below all, b

From: Galatas, Kate (CDC/OD/OADC)
Sent: Tuesday, August 19, 2014 9:56 AM
To: Skinner, Thomas W. (CDC/OD/OADC); Reynolds, Barbara S. (CDC/OD/OADC); Tumpey, Abbigail (CDC/OID/NCEZID); Hoskins, Sharon (K.D.) (CDC/OD/OADC); Sheedy, Kristine (CDC/OID/NCIRD)
Cc: Daniel, Katherine Lyon (CDC/OD/OADC); Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: RE: Focus Autism News Release _ CDC whistleblower

Thanks, Tom … plus Betsy for awareness within NCBDDD, in case they haven't seen … but, given it's Brian Hooker, I suspect she knows ☺

Kate Galatas, MPH
Deputy Associate Director for Communication
Centers for Disease Control and Prevention
Cell: (b)(6)
Email: kkg2@cdc.gov

From: Skinner, Thomas W. (CDC/OD/OADC)
Sent: Tuesday, August 19, 2014 9:05 AM
To: Reynolds, Barbara S. (CDC/OD/OADC); Tumpey, Abbigail (CDC/OID/NCEZID); Hoskins, Sharon (K.D.) (CDC/OD/OADC); Sheedy, Kristine (CDC/OID/NCIRD); Galatas, Kate (CDC/OD/OADC)
Cc: Daniel, Katherine Lyon (CDC/OD/OADC)
Subject: FW: Focus Autism News Release _ CDC whistleblower

FYI

Tom Skinner
Senior Press Officer
News Media Branch
Division of News and Electronic Media
www.cdc.gov/media
office: 404-639-7851
cell: (b)(6)

From: Falco, Miriam [mailto:Miriam.Falco@turner.com]
Sent: Tuesday, August 19, 2014 8:55 AM
To: Skinner, Thomas W. (CDC/OD/OADC)
Subject: FW: Focus Autism News Release _ CDC whistleblower

Hi Tom,
Have you seen this.. it was sent to me by a colleague…
Just curious.
Thanks,
Miriam

FOR IMMEDIATE RELEASE CONTACT: Jenny Kefauver
MONDAY 08/18/2014 (703) 842-7405/(703) 850-3533

A Study by Focus Autism Foundation Finds:

CDC Whistleblower Reveals Widespread Manipulation of Scientific Data and Top-Down Pressure on CDC Scientists to Support the Fraudulent Application of Government Policies on Vaccine Safety

Whistleblower Says CDC Knew in 2003 of Higher Autism Rate Among African-American Boys Receiving MMR Shot Earlier Than 36 Months

WATCHUNG, NJ--(Marketwired - August 18, 2014) - A top research scientist working for the **Centers for Disease Control and Prevention (CDC)** played a key role in helping **Dr. Brian Hooker** of the **Focus Autism Foundation** uncover data manipulation by the CDC that **obscured a higher incidence of autism in African-American boys**. The whistleblower came to the attention of Hooker, a PhD in biochemical engineering, after he had made a Freedom of Information Act (FOIA) request for original data on the DeStefano et al MMR (measles, mumps, rubella) and autism study.

Dr. Hooker's study, published August 8 in the peer-reviewed scientific journal Translational Neurodegeneration, **shows that African-American boys receiving their first MMR vaccine before 36 months of age are 3.4 times more likely to develop autism vs. after 36 months.**

According to Dr. Hooker, the CDC whistleblower informant -- who wishes to remain anonymous -- guided him to evidence that a statistically significant relationship between the age the MMR vaccine was first given and autism incidence in African-American boys was hidden by CDC researchers. After data were gathered on 2,583 children living in Atlanta, Georgia who were born between 1986 and 1993, CDC researchers excluded children that did not have a valid State of Georgia birth certificate -- reducing the sample size being studied by 41%. Hooker explains that by introducing this arbitrary criteria into the analysis, the cohort size was sharply reduced, eliminating the statistical power of the findings and negating the strong MMR-autism link in African American boys.

Dr. Hooker has worked closely with the CDC whistleblower, and he viewed highly sensitive documents related to the study via Congressional request from U.S. Representative Darrell Issa, Chairman of the House Oversight and Government Reform Committee. The CDC documents from Congress and discussions that Hooker had with the whistleblower reveal widespread manipulation of scientific data and top-down pressure on CDC scientists to support fraudulent application of government policies on vaccine safety. Based on raw data used in the 2004 DeStefano et al study obtained under FOIA, Dr. Hooker found that the **link between MMR vaccination and autism in African-American boys was obscured by the introduction of irrelevant and unnecessary birth certificate criteria** -- ostensibly to reduce the size of the study.

The results of the original study first appeared in the journal Pediatrics which receives financial support from vaccine makers via advertising and direct donations, according to a CBS News report. The DeStefano et al study is widely used by the CDC and other public health organizations to dismiss any link between vaccines and autism -- a neurological disorder on the rise.

Dr. Hooker stated "The CDC knew about the relationship between the age of first MMR vaccine and autism incidence in African-American boys as early as 2003, but chose to cover it up." The whistleblower confirmed this.

When asked if there could be any scientific basis for excluding children born outside of Georgia, Hooker responded, "I know of none, and none has been provided by the authors of the DeStefano study." He added, "The exclusion is reminiscent of tactics historically used to deprive African-Americans of the vote by requiring valid birth certificates."

Dr. Hooker concluded further study is needed to determine why this specific effect (3.4-fold increase when MMR is administered prior to 36 months) is seen exclusively in African-American males, and determine whether delaying the first MMR vaccination should be advised for this population. A link between the MMR vaccine and autism has been conceded in cases compensated by the National Vaccine Injury Compensation Program.

The CDC whistleblower informant, who has worked for the government agency for over a decade, remarked to Dr. Hooker in phone calls: "We've missed ten years of research because the CDC is so paralyzed right now by anything related to autism. They're not doing what they should be doing because they're afraid to look for things that might be associated." The whistleblower alleges criminal wrongdoing of his supervisors, and he expressed deep regret about his role in helping the CDC hide data.

According to David Lewis, PhD, former senior-level microbiologist with the U.S. EPA's Office of Research & Development, skewing scientific data to support government policies is a major problem at federal agencies, including EPA, CDC, and USDA. Lewis, who was terminated by EPA for publishing papers in Nature that questioned the science the agency uses to support certain regulations, believes top-down pressure on federal scientists and researchers working on government-funded projects in academia is jeopardizing public health.

"Working for the government is no different than working for corporations. You either toe the line or find yourself looking for another way to make a living," Lewis says. "No one would be surprised if Merck published unreliable data supporting the safety of its products. Why would anyone be surprised that the CDC is publishing skewed data to conclude that the vaccines it recommends are safe? We need a better system, where scientists are free to be honest."
The Focus Autism Foundation is dedicated to providing information to the public that exposes the cause or causes of the autism epidemic and the rise of chronic illness -- focusing on the role of vaccinations. Learn more at www.Focusautism.org

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Fri, 20 Mar 2015 09:07:51 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Thank you very much Coleen.

Elizabeth A. Belser-Vega

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, March 19, 2015 5:59 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Hi Elizabeth: Pls see attached. Thx, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Thursday, March 19, 2015 9:23 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Hi Coleen,

Following up on this one. I need the info below please.

Thanks,

Elizabeth A. Belser-Vega

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Thursday, February 26, 2015 10:22 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Hi Coleen,

Thanks for filling this form out. Unfortunately for this request they are not wanting the typical cost estimate form but instead want answers to the detailed questions below. Also please remember to search for all the terms separately- so search for autism and try to estimate how many pages you would have, and then search separately for William Thompson etc.

For this particular case, you may submit the volume estimate and description in either Word or Excell format.
1. Indicate the number of emails AND the general subject matter (i.e. meeting requests, discussions on data, newsletters, etc.)
2. Indicate the number of all other electronic records (Word, Excel, PowerPoint, etc.), broken down by type AND general subject matter. (E.g., 500 Excel spreadsheets -- data, study participant lists, etc.; 97 PowerPoint presentations ---internal presentations to CDC staff, conference presentationts, etc.; 275 Word documents --- draft manuscripts, reports)
3. Indicate the number of pages of paper records, if any. (1 inch of stacked paper = 250 pages)
4. Note any special concerns regarding the release of the records (i.e., records contain PII; some records are deliberative and pre-decisional; other agency records are included, etc.)

Elizabeth A. Belser-Vega

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, February 25, 2015 5:41 PM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Elizabeth: I only included the search time costs. I assume there will be other costs due to the process and review that your grp does. Thanks, COleen

---

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, February 24, 2015 4:41 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD)
Subject: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Good Afternoon Coleen, Marshalyn, Bill, and Laura,

We have received a new FOIA request (attached). As this is a vast request we are being asked to provide a cost estimate by answering the detailed questions below. Originally the FOIA office was asking us to poll everyone, but I was able to get them to agree to accept a cost estimate from the 5 people in our center who this request is most relevant to (you all and Diana Schendel's records). The FOIA office is planning on going back to the requestor and working with them to narrow their scope to determine what they are actually looking for, but has asked us to provide this first so that they can demonstrate to the requestor the vastness of what this response would include.

Please take special note of this part:
As this is a request for cost estimate only, there will be no extension of the due date (March 7, 1015). Please provide your volume estimate and record description by this date.

Normally for a cost estimate we fill out a form, but in this case they are asking for answers to the questions below. We will estimate the amount of Diana Schendel documents we have on hand but we will also need someone who has access to her emails (is that Phyllis) to do a search there for these terms.

Please let me know if you have any questions or need assistance in anyway.

Elizabeth A. Belser-Vega

From: FOIA Requests (CDC)
Sent: Monday, February 23, 2015 11:20:37 AM (UTC-05:00) Eastern Time (US & Canada)
To: CDC NCBDDD Data Request (CDC); Corley, Janice (CDC/OID/NCIRD)
Subject: Memo - Request for Cost Estimate Only - Request # 15-00433-FOIA

Request for **COST ESTIMATE ONLY** for Request # '15-00433-FOIA'. Due date: March 9, 2015.

The enclosed request seeks records related to any of the following terms: William Thompson, MMR, autism. (Note that the request doesn't seek records wherein those 3 terms intersect.)

We anticipate that there will be a large volume of records responsive to this request. Therefore, **we are asking both programs to provide the FOIA Office with an estimate and general description of the responsive records.** [Please note that the requester is a member of the media and therefore will not have to pay fees. Thus we are only interested in learning the volume and types of documents in your Center that are responsive to the request.]

For this particular case, you may submit the volume estimate and description in either Word or Excell format.
1. Indicate the number of emails AND the general subject matter (i.e. meeting requests, discussions on data, newsletters, etc.)
2. Indicate the number of all other electronic records (Word, Excel, PowerPoint, etc.), broken down by type AND general subject matter. (E.g., 500 Excel spreadsheets -- data, study participant lists, etc.; 97 PowerPoint presentations ---internal presentations to CDC staff, conference presentationts, etc.; 275 Word documents --- draft manuscripts, reports)

3. Indicate the number of pages of paper records, if any. (1 inch of stacked paper = 250 pages)
4. Note any special concerns regarding the release of the records (i.e., records contain PII; some records are deliberative and pre-decisional; other agency records are included, etc.)

Please be as honest as possible in your estimate and description as this information is needed by the FOIA Office in order to negotiate with the requester. Our negotiations are only as good as the information you provide to us.

As this is a request for cost estimate only, there will be no extension of the due date (March 7, 1015). Please provide your volume estimate and record description by this date.

If you have any questions, please contact Laura Spencer in the FOIA Office.

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Mon, 2 Mar 2015 11:20:08 -0500
To: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Hi Bill,

I did check with the FOIA office about this and here is their guidance:
The way the request is written, the first term "William Thompson" would include all of Bill's emails and files (he can tally up what is in his folders and archived folders), as well as email to/from him, and with his name in the subject line or body of the message as well.

I think that matches what you suggested below.

Please let me know if you have any other questions.

Elizabeth A. Belser-Vega

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Monday, March 02, 2015 10:58 AM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Elizabeth,

If I am interpreting this request accurately, it looks like this reporter is asking for all of my e-mails (since they all contain my name) regardless of topic since 2004 as well as any other files that includes my name.

Is that correct and is that what you/CDC want me to provide an estimate for?

Thanks,

Bill

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, February 24, 2015 4:41 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD);

Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD)
Subject: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Good Afternoon Coleen, Marshalyn, Bill, and Laura,

We have received a new FOIA request (attached). As this is a vast request we are being asked to provide a cost estimate by answering the detailed questions below. Originally the FOIA office was asking us to poll everyone, but I was able to get them to agree to accept a cost estimate from the 5 people in our center who this request is most relevant to (you all and Diana Schendel's records). The FOIA office is planning on going back to the requestor and working with them to narrow their scope to determine what they are actually looking for, but has asked us to provide this first so that they can demonstrate to the requestor the vastness of what this response would include.

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Normally for a cost estimate we fill out a form, but in this case they are asking for answers to the questions below. We will estimate the amount of Diana Schendel documents we have on hand but we will also need someone who has access to her emails (is that Phyllis) to do a search there for these terms.

Please let me know if you have any questions or need assistance in anyway.

Elizabeth A. Belser-Vega

From: FOIA Requests (CDC)
Sent: Monday, February 23, 2015 11:20:37 AM (UTC-05:00) Eastern Time (US & Canada)
To: CDC NCBDDD Data Request (CDC); Corley, Janice (CDC/OID/NCIRD)
Subject: Memo - Request for Cost Estimate Only - Request # 15-00433-FOIA

Request for **COST ESTIMATE ONLY** for Request # '15-00433-FOIA'. Due date: March 9, 2015.

The enclosed request seeks records related to any of the following terms: William Thompson, MMR, autism. (Note that the request doesn't seek records wherein those 3 terms intersect.)

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For this particular case, you may submit the volume estimate and description in either Word or Excell format.

1. Indicate the number of emails AND the general subject matter (i.e. meeting requests, discussions on data, newsletters, etc.)
2. Indicate the number of all other electronic records (Word, Excel, PowerPoint, etc.), broken down by type AND general subject matter. (E.g., 500 Excel spreadsheets -- data, study participant lists, etc.; 97 PowerPoint presentations ---internal presentations to CDC staff, conference presentationts, etc.; 275 Word documents --- draft manuscripts, reports)
3. Indicate the number of pages of paper records, if any. (1 inch of stacked paper = 250 pages)
4. Note any special concerns regarding the release of the records (i.e., records contain PII; some records are deliberative and pre-decisional; other agency records are included, etc.)

Please be as honest as possible in your estimate and description as this information is needed by the FOIA Office in order to negotiate with the requester. Our negotiations are only as good as the information you provide to us.

As this is a request for cost estimate only, there will be no extension of the due date (March 7, 1015). Please provide your volume estimate and record description by this date.

If you have any questions, please contact Laura Spencer in the FOIA Office.

From: Thompson, William (Bill) (CDC/ONDIEH/NCBDDD)
Sent: Tue, 3 Mar 2015 11:58:27 -0500
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Frey, Meghan T. (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

That is a very helpful clarification Elizabeth! Especially for me. ☺

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, March 03, 2015 11:53 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)
Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD); Moore, Cynthia (CDC/ONDIEH/NCBDDD); Fehrenbach, Nicole (CDC/ONDIEH/NCBDDD); Frey, Meghan T. (CDC/ONDIEH/NCBDDD)
Subject: RE: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Hi All,

I wanted to share a little more information that I received from the FOIA office. The point of doing this cost estimate is to show the impact that this request would have-

Yes, it is massive. The SMEs are free to take a small sample and then extrapolate for an estimate to cover the entire time frame of 2004-2015. They don't have to run 9 or 10 email searches for each year.

We don't have to have a hard count based on the SMEs conducting a detailed search at this time. We just need them to take a look at their files and estimate the total volume of what they have. We need something from them that demonstrates how massive such a universe of records is. We can then use that (versus just our general sense of things) to negotiate with the requester and identify the information she truly wants.

Please let me know if you have any questions.

Elizabeth A. Belser-Vega

From: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, February 24, 2015 4:41 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Nichols, Phyllis (CDC/ONDIEH/NCBDDD); Thompson, William (Bill) (CDC/ONDIEH/NCBDDD); Schieve, Laura (CDC/ONDIEH/NCBDDD)

Cc: Lucido, Sal (CDC/ONDIEH/NCBDDD); Lee, Kinzie (CDC/ONDIEH/NCBDDD); Wojcik, Joanne (CDC/ONDIEH/NCBDDD) (CTR); Smith, Kimberly E. (CDC/ONDIEH/NCBDDD)
Subject: FOIA Request for Cost Estimate Only - Request # 15-00433-FOIA

Good Afternoon Coleen, Marshalyn, Bill, and Laura,

We have received a new FOIA request (attached). As this is a vast request we are being asked to provide a cost estimate by answering the detailed questions below. Originally the FOIA office was asking us to poll everyone, but I was able to get them to agree to accept a cost estimate from the 5 people in our center who this request is most relevant to (you all and Diana Schendel's records). The FOIA office is planning on going back to the requestor and working with them to narrow their scope to determine what they are actually looking for, but has asked us to provide this first so that they can demonstrate to the requestor the vastness of what this response would include.

Please take special note of this part:
As this is a request for cost estimate only, there will be no extension of the due date (March 7, 1015). Please provide your volume estimate and record description by this date.

Normally for a cost estimate we fill out a form, but in this case they are asking for answers to the questions below. We will estimate the amount of Diana Schendel documents we have on hand but we will also need someone who has access to her emails (is that Phyllis) to do a search there for these terms.

Please let me know if you have any questions or need assistance in anyway.

Elizabeth A. Belser-Vega

From: FOIA Requests (CDC)
Sent: Monday, February 23, 2015 11:20:37 AM (UTC-05:00) Eastern Time (US & Canada)
To: CDC NCBDDD Data Request (CDC); Corley, Janice (CDC/OID/NCIRD)
Subject: Memo - Request for Cost Estimate Only - Request # 15-00433-FOIA

Request for **COST ESTIMATE ONLY** for Request # '15-00433-FOIA'. Due date: March 9, 2015.

The enclosed request seeks records related to any of the following terms: William Thompson, MMR, autism. (Note that the request doesn't seek records wherein those 3 terms intersect.)

We anticipate that there will be a large volume of records responsive to this request. Therefore, **we are asking both programs to provide the FOIA Office with an estimate and general description of the responsive records.** [Please note that the requester is a member of the media and therefore will not have to pay fees. Thus we are only interested in learning the volume and types of documents in your Center that are responsive to the request.]

For this particular case, you may submit the volume estimate and description in either Word or Excell format.
1. Indicate the number of emails AND the general subject matter (i.e. meeting requests, discussions on data, newsletters, etc.)

2. Indicate the number of all other electronic records (Word, Excel, PowerPoint, etc.), broken down by type AND general subject matter. (E.g., 500 Excel spreadsheets -- data, study participant lists, etc.; 97 PowerPoint presentations ---internal presentations to CDC staff, conference presentationts, etc.; 275 Word documents --- draft manuscripts, reports)
3. Indicate the number of pages of paper records, if any. (1 inch of stacked paper = 250 pages)
4. Note any special concerns regarding the release of the records (i.e., records contain PII; some records are deliberative and pre-decisional; other agency records are included, etc.)

Please be as honest as possible in your estimate and description as this information is needed by the FOIA Office in order to negotiate with the requester. Our negotiations are only as good as the information you provide to us.

As this is a request for cost estimate only, there will be no extension of the due date (March 7, 1015). Please provide your volume estimate and record description by this date.

If you have any questions, please contact Laura Spencer in the FOIA Office.

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 17 Sep 2014 20:26:33 +0000
To: Cono, Joanne (CDC/OD/OADS)
Subject: Re: Follow up mtg

Ok. Will loop you in with future mtgs.

Sent from my iPad

On Sep 17, 2014, at 3:25 PM, "Cono, Joanne (CDC/OD/OADS)" <bzc6@cdc.gov> wrote:

Hi Coleen,

Sorry to have missed your call. I would be glad to participate in any future sessions, but tomorrow I have an appointment at 5:00 that will keep me from being able to join you.

Thanks,
Joanne

-----Original Appointment-----
From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, September 17, 2014 2:23 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: FW: Follow up mtg
When: Thursday, September 18, 2014 4:30 PM-5:30 PM (UTC-05:00) Eastern Time (US & Canada).
Where: 1825, Century Center, Director's Conference rm

Hi Joanne: I just spoke with Harold. Frank DeStefano, Marshalyn Yeargin Allsopp and I are meeting tomorrow to discuss the analysis on the MMR and autism paper. If you can participate would welcome your engagement tomorrow or at future meetings. Thx, Coleen

-----Original Appointment-----
From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, September 17, 2014 11:26 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD); Yeargin-Allsopp, Marshalyn (CDC/ONDIEH/NCBDDD); Destefano, Frank (CDC/OID/NCEZID); Autry, Andrew (CDC/ONDIEH/NCBDDD)
Subject: Follow up mtg
When: Thursday, September 18, 2014 4:30 PM-5:30 PM (UTC-05:00) Eastern Time (US & Canada).
Where: 1825, Century Center, Director's Conference rm

Please let me know if this time will work – difficult to read all of your calendars. thanks

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 23 Oct 2014 21:34:04 +0000
To: Cono, Joanne (CDC/OD/OADS)
Subject: RE: Follow up

Will do. thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Cono, Joanne (CDC/OD/OADS)
Sent: Thursday, October 23, 2014 4:16 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: FW: Follow up

Coleen,

You had asked me for information about the possible mechanisms for providing public access to the CDC datasets, because of Dr. Kemper's request. From your response below, I wasn't sure if that's been resolved - I believe Sudevi was looking into it; it's best that you follow-up with her. This is an issue separate from securing the data for the internal proceedings.

Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, October 23, 2014 3:28 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: RE: Follow up

Let me ask Andy if all the variables used in the 2004 are available on the public use dataset. Given the variables are categorized (i.e., there are ages at vaccination etc. instead of exact dates), a 'reanalysis' based on the public use dataset may get them close. Do you want them to have the ability to get an exact findings or a fairly good ballpark one?

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Cono, Joanne (CDC/OD/OADS)
Sent: Thursday, October 23, 2014 1:15 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Follow up

Thanks Coleen. So to be clear about what else may need follow-up, does this public use dataset contain the data that external groups would need to replicate the analysis in question?

Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thursday, October 23, 2014 12:35 PM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Follow up

Joanne: Just an amendment to the info on the public use dataset. I went back to the data documentation and contrary to our programmer's recollection (that is what happens after 10 yrs) the public use dataset does include the birth certificate info (although with select variables categorized (i.e., birthweight) rather than continuous.)

Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
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1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Cono, Joanne (CDC/OD/OADS)
Sent: Tuesday, October 21, 2014 6:16 PM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: Follow up

Coleen,

Thanks for your patience. Sorry I missed your call earlier today. (b)(5) (b)(5) . Your plan sounds fine. Let's talk tomorrow about the volume of records and how they are secured at the moment – I'll call you early in the day.

Please also tell me – is there a public use dataset that is reflective of that used in the 2004 study?

Thanks,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, October 17, 2014 6:21 AM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Fwd: Follow up

Joanne: To f/u on my earlier email to you about the FOIA request pertaining to the same set of records you requested for the inventory we have been given an extension of 6 weeksfrommthe FOIA folk but nonetheless they have been asked us to begin preparing the records which includes copying and making PDFs. (See Sudevi's email below.)

(b)(5)

Thx

Sent from my iPad

Begin forwarded message:

From: "Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)" <smd3@cdc.gov>
Date: October 16, 2014 at 4:17:10 PM EDT
To: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Subject: FW: Follow up

(b)(5)

From: Ghosh, Sudevi (CDC/OCOO/OGC)
Sent: Thursday, October 16, 2014 10:50 AM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Cc: Ford, Kenya S. (CDC/OCOO/OGC)
Subject: Follow up

Hi Elizabeth,

(b)(5)

Sudevi

Sudevi N. Ghosh
Senior Attorney
HHS Office of the General Counsel

Public Health Division
Centers for Disease Control and Prevention Branch
(404) 639-7200 (main)
(404) 639-7016 (direct)
sghosh@cdc.gov

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Wed, 22 Oct 2014 10:03:43 +0000
To: Cono, Joanne (CDC/OD/OADS)
Subject: Re: Follow up

Hi Joanne: thanks, I am free from 9-10 and after 3:30 today. There is a public use dataset, but it does not contain the birth certificate data because of the confidentiality agreement with the state on access.

Talk with you later,

Coleen

Sent from my iPad

On Oct 21, 2014, at 6:15 PM, Cono, Joanne (CDC/OD/OADS) <bzc6@cdc.gov> wrote:

Coleen,

Thanks for your patience. Sorry I missed your call earlier today. (b)(5) – (b)(5) Your plan sounds fine. Let's talk tomorrow about the volume of records and how they are secured at the moment – I'll call you early in the day.

Please also tell me – is there a public use dataset that is reflective of that used in the 2004 study?

Thanks,
Joanne

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, October 17, 2014 6:21 AM
To: Cono, Joanne (CDC/OD/OADS)
Subject: Fwd: Follow up

Joanne: To f/u on my earlier email to you about the FOIA request pertaining to the same set of records you requested for the inventory we have been given an extension of 6 weeksfrommthe FOIA folk but nonetheless they have been asked us to begin preparing the records which includes copying and making PDFs. (See Sudevi's email below.)

(b)(5)

Thx

Sent from my iPad

Begin forwarded message:

From: "Dulin, Stephanie M. (CDC/ONDIEH/NCBDDD)" <smd3@cdc.gov>
Date: October 16, 2014 at 4:17:10 PM EDT
To: "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Subject: FW: Follow up

(b)(5)

From: Ghosh, Sudevi (CDC/OCOO/OGC)
Sent: Thursday, October 16, 2014 10:50 AM
To: Belser-Vega, Elizabeth (CDC/ONDIEH/NCBDDD)
Cc: Ford, Kenya S. (CDC/OCOO/OGC)
Subject: Follow up

Hi Elizabeth,

(b)(5)

Sudevi

Sudevi N. Ghosh
Senior Attorney
HHS Office of the General Counsel
Public Health Division
Centers for Disease Control and Prevention Branch
(404) 639-7200 (main)
(404) 639-7016 (direct)
sghosh@cdc.gov

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

(b)(6) ; (b)(7)(C)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Thu, 9 Oct 2014 13:26:32 +0000
To: Alex Kemper, M.D.
Cc: Mitchell, Betsy (CDC/ONDIEH/NCBDDD)
Subject: RE: Follow-up Regarding the 2004 Autism Paper

Alex: I have sent your request to our communications colleagues who will f/u on your request. Pls feel free to follow up directly with Betsy Mitchell, the NCBDDD Assoc Dir for Communications, if you do not heard back.

Thanks, Coleen

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

From: Alex Kemper, M.D. [mailto:(b)(6)@duke.edu]
Sent: Thursday, October 09, 2014 8:25 AM
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: Follow-up Regarding the 2004 Autism Paper

Dr. Boyle,

I hope you are well.

I was hoping that you could email me a copy of the protocol used for the 2004 PEDIATRICS paper on MMR and autism. I requested the protocol from Dr. Reynolds, but have not heard back.

Also, as I understand it, the data used in that paper are publicly available upon request. Can you let me know what the process is to get access to those data?

Thanks,

Alex R. Kemper, MD, MPH, MS
Deputy Editor, PEDIATRICS

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Fri, 22 Aug 2014 21:00:48 +0000
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: Re: For review: Expanded but still brief CDC statement/Hooker

Excellent. Cc me, Stephanie and Betsy on any cmts.

Sent from my iPad

On Aug 22, 2014, at 4:59 PM, "Moore, Cynthia (CDC/ONDIEH/NCBDDD)" <cam0@cdc.gov> wrote:

Yes, I just got back from talking with Stephanie. I'll do it now.

Cindy

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Friday, August 22, 2014 4:59 PM
To: Moore, Cynthia (CDC/ONDIEH/NCBDDD)
Subject: Fwd: For review: Expanded but still brief CDC statement/Hooker

Can you review too? Let me know if you are picking up this msg.

Sent from my iPad

Begin forwarded message:

From: "Coffin, Nicole (CDC/OID/NCEZID)" <ndc3@cdc.gov>
Date: August 22, 2014 at 4:38:56 PM EDT
To: "Mitchell, Betsy (CDC/ONDIEH/NCBDDD)" <bhm0@cdc.gov>, "Boyle, Coleen (CDC/ONDIEH/NCBDDD)" <cab3@cdc.gov>
Cc: "Weinbaum, Cindy (CDC/OID/NCEZID)" <chw4@cdc.gov>, "Destefano, Frank (CDC/OID/NCEZID)" <fxd1@cdc.gov>, "Fisher, Angela H. (CDC/OID/NCEZID) (CTR)" <iwg7@cdc.gov>, "Brower, Melissa (CDC/OID/NCEZID)" <ggk5@cdc.gov>, "Gonzalez, Belsie (CDC/OD/OADC)" <fqi1@cdc.gov>
Subject: For review: Expanded but still brief CDC statement/Hooker

Betsy, Coleen,
I am stepping in on this issue as Melissa is staffing an Ebola interview. Please review the statement ASAP. Once you have provided comments, Belsie Gonzalez will work with Barbara Reynolds to clear the statement for use.
Best,
Nicole

For BB Reading:

(b)(5)

From: Harden, Camille (CDC/ONDIEH/NCBDDD)
Sent: Wed, 30 Mar 2016 17:00:48 -0400
To: Shapira, Stuart (CDC/ONDIEH/NCBDDD); Ruben, Wendy (CDC/ONDIEH/NCBDDD); Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD); Chaney, Sascha (CDC/ONDIEH/NCEH); Chan, C. Leah (CDC/ONDIEH/NCBDDD); Hunter, Karen (CDC/ONDIEH/NCBDDD); Sniezek, Joe (CDC/ONDIEH/NCBDDD); Dowling, Nicole (CDC/ONDIEH/NCBDDD); Boyle, Coleen (CDC/ONDIEH/NCBDDD); Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD); Perou, Ruth (CDC/ONDIEH/NCBDDD); Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD); Baio, Jon (CDC/ONDIEH/NCBDDD)
Cc: Hillard, Christina (CDC/ONDIEH/NCBDDD) (CTR); Atkins, Bret (CDC/ONDIEH/NCBDDD); Moran, Belen (CDC/OD/OADC)
Subject: RE: FYI: the statement

Agree – no issues.

From: Shapira, Stuart (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, March 30, 2016 4:50 PM
To: Ruben, Wendy (CDC/ONDIEH/NCBDDD) <hif0@cdc.gov>; Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Sniezek, Joe (CDC/ONDIEH/NCBDDD) <jes6@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Harden, Camille (CDC/ONDIEH/NCBDDD) <eah4@cdc.gov>; Perou, Ruth (CDC/ONDIEH/NCBDDD) <rzp4@cdc.gov>; Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD) <dqc3@cdc.gov>; Baio, Jon (CDC/ONDIEH/NCBDDD) <xzb1@cdc.gov>
Cc: Hillard, Christina (CDC/ONDIEH/NCBDDD) (CTR) <vns3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Moran, Belen (CDC/OD/OADC) <isb8@cdc.gov>
Subject: RE: FYI: the statement

Works for me.

--Stuart

From: Ruben, Wendy (CDC/ONDIEH/NCBDDD)
Sent: Wednesday, March 30, 2016 3:57 PM
To: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD) <lbz7@cdc.gov>; Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Sniezek, Joe (CDC/ONDIEH/NCBDDD) <jes6@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Harden, Camille (CDC/ONDIEH/NCBDDD) <eah4@cdc.gov>; Perou, Ruth (CDC/ONDIEH/NCBDDD) <rzp4@cdc.gov>; Shapira, Stuart (CDC/ONDIEH/NCBDDD) <cso6@cdc.gov>; Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD) <dqc3@cdc.gov>; Baio, Jon (CDC/ONDIEH/NCBDDD) <xzb1@cdc.gov>
Cc: Hillard, Christina (CDC/ONDIEH/NCBDDD) (CTR) <vns3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Moran, Belen (CDC/OD/OADC) <isb8@cdc.gov>
Subject: RE: FYI: the statement

Hi Everyone,

Given the narrow focus of the Partner Tele-Briefing call, we would recommend using the statement below to redirect any questions. (b)(5)

(b)(5)

Does anybody have concerns about this approach or anyone who needs to clear it?

Thank you for your question. CDC shares with parents and others great concern about the number of children with autism spectrum disorder. We'd like to focus the limited time on this call on the findings and implications of today's report.

Thanks,
Wendy

Wendy Ruben, MS, CHES
Hif0@cdc.gov; 404-498-0230

From: Baldwin, Laura Zauderer (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, March 29, 2016 3:56 PM
To: Chaney, Sascha (CDC/ONDIEH/NCEH) <zpo7@cdc.gov>; Chan, C. Leah (CDC/ONDIEH/NCBDDD) <inu4@cdc.gov>; Ruben, Wendy (CDC/ONDIEH/NCBDDD) <hif0@cdc.gov>; Hunter, Karen (CDC/ONDIEH/NCBDDD) <ksh7@cdc.gov>; Sniezek, Joe (CDC/ONDIEH/NCBDDD) <jes6@cdc.gov>; Dowling, Nicole (CDC/ONDIEH/NCBDDD) <ncd5@cdc.gov>; Boyle, Coleen (CDC/ONDIEH/NCBDDD) <cab3@cdc.gov>; Phoenix Weir, Ursula (CDC/ONDIEH/NCBDDD) <uap3@cdc.gov>; Harden, Camille (CDC/ONDIEH/NCBDDD) <eah4@cdc.gov>; Perou, Ruth (CDC/ONDIEH/NCBDDD) <rzp4@cdc.gov>; Shapira, Stuart (CDC/ONDIEH/NCBDDD) <cso6@cdc.gov>; Christensen, Deborah (Daisy) (CDC/ONDIEH/NCBDDD) <dqc3@cdc.gov>; Baio, Jon (CDC/ONDIEH/NCBDDD) <xzb1@cdc.gov>
Cc: Hillard, Christina (CDC/ONDIEH/NCBDDD) (CTR) <vns3@cdc.gov>; Atkins, Bret (CDC/ONDIEH/NCBDDD) <bja9@cdc.gov>; Moran, Belen (CDC/OD/OADC) <isb8@cdc.gov>
Subject: FYI: the statement

http://www.cdc.gov/vaccinesafety/concerns/autism/cdc2004pediatrics.html

The first few sentences from the statement are below. This is what is currently being shared externally.

CDC shares with parents and others great concern about the number of children with autism spectrum disorder.

CDC is committed to continuing to provide essential data on autism, search for factors that put children at risk for autism and look for possible causes. While doing so, we work to develop

resources that help identify children with autism as early as possible so they can benefit from intervention services.

Here are a few other helpful links from our NCIRD colleagues:

http://www.cdc.gov/vaccinesafety/concerns/autism.html

http://www.cdc.gov/vaccinesafety/pdf/cdcstudiesonvaccinesandautism.pdf

If there are any changes to this, I will keep you posted.

-Laura

Laura Baldwin (Zauderer)
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
Phone: 404-498-3976
Email: Lbz7@cdc.gov

From: Gonzalez, Belsie (CDC/OD/OADC)
Sent: Tue, 21 Oct 2014 10:21:48 -0400
To: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Subject: RE: f/u
Attachments: Data Documentation and Data Dictionary.pdf

Coleen,

The Appendix A on the document attached is the Data Sharing and Use Agreement Agreement Hooker signed. You might want to examine the whole document as the entire document was given to him when he requested the data.

Belsie

Belsie González, MPH
Senior Public Affairs Specialist

News Media Branch | Division of Public Affairs
Office of the Associate Director for Communication
Centers for Disease Control and Prevention (CDC)

From: Boyle, Coleen (CDC/ONDIEH/NCBDDD)
Sent: Tuesday, October 21, 2014 9:48 AM
To: Gonzalez, Belsie (CDC/OD/OADC)
Subject: f/u

Belsie: I am going to suggest that we add an email address for all requesters of the MMR—autism dataset. Right now we ask requesters to mail in their request. You can let Dr. Hooker and Kemper know that an email address will appear shortly on the website. thx

Coleen A. Boyle, PhD, MS hyg
Director
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Rd.
Atlanta, GA 30333

Ph: 404-498-3800
Fx: 404-498-3070
cboyle@cdc.gov
Note: Overnight delivery address: 1825 Century Center Blvd., Atlanta, GA 30345

Study of Age at First MMR Vaccination and Autism

Restricted Access Data Set

Data Documentation and Data Dictionary

Created by
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

January 30, 2004

This documentation was prepared in the CDC National Center on Birth Defects and Developmental Disabilities. Tanya Karapurkar-Bhasin and Andrew Autry of the Developmental Disabilities Team and William Thompson of the National Immunization Program developed this documentation. Andrew Autry of the Developmental Disabilities Team coordinated the technical preparation of the data set.

Please direct questions about the documentation or substantive questions about the data file should be directed to Tanya Karapurkar-Bhasin, Developmental Disabilities Team, CDC National Center on Birth Defects and Developmental Disabilities, 1600 Clifton Road, Atlanta, Georgia 30333 (404-498-3860) or William Thompson, CDC National Immunization Program, 1600 Clifton Road, Atlanta, Georgia 30333 (404-639-8200).

Please direct questions about access to and technical use of the data set to Andrew Autry, Developmental Disabilities Team, CDC National Center on Birth Defects and Developmental Disabilities, 1600 Clifton Road, Atlanta, Georgia 30333 (404-498-3860).

I. Overview of the Study

Since the initial study conducted by Wakefield et al. (1998) that proposed a causal link between measles-mumps-rubella (MMR) vaccination and autism, several epidemiologic studies have been conducted to examine this relationship. These studies have largely found no association between MMR vaccination and autism. In addition, after review of the existing scientific information about the MMR-autism hypothesis, the Institute of Medicine (IOM) rejected a causal association between the vaccination and autism. However, the IOM did suggest additional research be conducted to examine the relationship in subgroups of children with autism who may be at increased risk for developing the disorder following MMR vaccination.

To resolve speculation regarding the association between the MMR vaccine and autism and in light of the IOM recommendation, investigators from the Centers for Disease Control and Prevention (CDC) conducted a matched case-control study using the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) to look at this potential relationship. The main objective of this study was to compare ages at first MMR vaccination between children with autism and children who did not have autism in the total population and in selected subgroups, including children with regression in development (DeStefano et al., 2004).

II. Study Population and Study Design (including source of the data)

Children with autism were identified from the MADDSP Autism Surveillance Program in 1996. MADDSP monitors the rate of serious developmental disabilities such as autism, mental retardation, cerebral palsy, hearing loss, and vision impairment (Yeargin-Allsopp et al., 1992; Yeargin-Allsopp et al., 2003). MADDSP defined a child with autism as a child who was 3 to 10 years old during the 1996 study year (birth years 1986-1993), whose parent(s) or legal guardian(s) resided in the 5-county metropolitan Atlanta area at any time during the 1996 study year, and who displayed behaviors (as described by a qualified professional) consistent with the *Diagnostic Statistical Manual of Mental Disorders, 4th edition* (DSM-IV) criteria for autistic disorder, Pervasive Developmental Disorder, Not Otherwise Defined (PDD-NOS) (including atypical autism), or Asperger disorder on evaluations conducted through 1996 (Yeargin-Allsopp et al., 2003).

Children with autism were identified through screening and abstraction of source files at schools, hospitals, clinics, and specialty providers. Experts in the field of autism reviewed the abstracted information to make a final case determination based on the behavioral information in the abstracted record. The autism experts used a standardized behavioral coding scheme to determine the presence of behavioral characteristics consistent with the DSM-

IV criteria for autism spectrum disorder (ASD) (Yeargin-Allsopp et al., 2003). Based on this process, MADDSP identified 987 children with autism who were between the ages of 3-10 years during the study year of 1996 (birth years 1986-1993).

The study population used for the present study was derived from the 987 children with autism identified by MADDSP. From 1999 to 2001 study investigators were only able to locate school records with immunization forms on file for 660 children with autism. Reasons for why the immunization records for the remaining children could not be located can be found in a detailed report describing this study (DeStefano et al., 2004).

A total of 36 case children were excluded from the total sample of 660 children with autism. Seventeen children were excluded from the study because the investigators could not identify matched controls for them. This brought the sample of case children to 643. Further, case and control children were excluded from the study if they were missing a vaccination form (15 case and 14 control children), or if the vaccination forms did not list at least one diphtheria-tetanus-pertussis (DTP) vaccine by 2 years of age or at least one MMR vaccination at any age (4 case children and 1 control child). After all of the exclusions, the study sample was reduced to 624 children with autism and 1824 control children. It is important to note that children who had either religious or medical exemptions for vaccinations were not excluded from this study (1 case and 1 control). In summary, to be included in the study sample a child with autism had to have a valid MMR vaccination date from a school immunization form, a DTP vaccination by age 2 from the school immunization form, or an immunization exemption form.

As mentioned previously, a matched case-control study design was used for this study. A 3:1 control to case ratio was used and was achieved for 97% of the cases; the remaining children with autism had fewer matched control children. Control children were selected from regular education programs and were matched to case children based on age in 1996 (within 1 year), gender, and school of attendance at the time of abstraction. It was not verified that the control child was in the school in 1996 or was in the state of Georgia in 1996. The only requirements for control selection were the matching requirements stated above.

In keeping with the purposes of the study, the investigators identified three main subgroups for analysis. These subgroups, which were not mutually exclusive, were 1) children with loss of age-appropriate developmental skills (regression) or appropriate skills that failed to progress (plateau); 2) children without developmental delay prior to 1 year of age or a pre-existing condition; and 3) children with and without mental retardation (MR) as a co-existing disability.

As defined in the report by DeStefano et al. (2004), children without any indication of developmental delay before 1 year of age were children who did not lack any speech at appropriate ages including cooing and babbling, and were socially responsive in the first year of life. Children without a pre-existing condition included children who did not have a major birth defect, a co-occurring disability, or a major perinatal or postnatal insult (e.g., infection, injury) that could have contributed to developmental delays (DeStefano et al., 2004). Children without indication of developmental delay prior to 1 year of age and children without a pre-existing condition were grouped into a single group. Determination of whether or not a child had MR was based on whether or not the child met the MADDSP case definition for MR, defined as having an IQ of 70 or less on the most recent psychometric test.

The association between the age at first MMR vaccination and autism was also assessed in the total and birth certificate samples according to gender and age. Further, in the birth certificate sample only, the study investigators examined the association between the age at first MMR vaccination and autism according to race, birth weight, and select maternal characteristics (e.g., maternal age and maternal education). Information on these variables could only be obtained from the child's birth certificate, which is why these particular subgroup analyses were limited to the birth certificate sample only.

Tables 1-5 of this documentation provide frequency counts that requesting researchers can use to authenticate the data received as being the same data used in the study. The total number of children with autism in each of these case subgroups (total and birth certificate samples) can be found in Tables 4 and 5.

III. Data Collection Activities and Data Collection Instruments

For the purpose of this study, trained abstractors collected vaccination histories for both case and control children from the standardized state immunization forms that are required for all children who attend school and early intervention programs in Georgia. The forms are placed in each student's permanent school file that is kept at the school where the child is enrolled. In 1996, Georgia law required the following vaccines for children: 1) at least 3 doses of either DTP, DT, or DTaP; 2) a combination of at least 3 doses of either trivalent oral polio vaccine (TOPV) or enhanced potency inactivated polio vaccine (EIPV); and 3) at least one dose of measles, mumps, and rubella vaccine in the form of either the MMR, MR, or single antigen vaccines. Effective with the 1994-95 school year, for entrance into sixth grade, a child needed to have received at least one additional dose of the MMR vaccine, for a total of two MMR vaccines administered on or after the child's first birthday and at least one month apart. Children usually receive their first dose of the combined MMR vaccination by 15 months of age. A

child can also meet the measles and rubella requirement with lab confirmation of the presence of protective levels of antibodies. Hepatitis B vaccine and Hib vaccine were not required by the school systems at any time during the study.

Other information collected from the vaccination forms included location of vaccine administration, the physician or qualified examiner who administered the vaccine, and information regarding the administration of vaccines not required for school entry or additional doses of a vaccine that was required. Data regarding medical and religious vaccination exemptions were also collected.

For children with autism, additional information related to developmental disabilities was obtained from MADDSP data files. This information included the presence of other developmental disabilities, epilepsy, and IQ level (for categorization of MR). In addition, investigators identified major birth defects among the case children by linking with CDC's Metropolitan Atlanta Congenital Defects Program, a population-based surveillance program of major birth defects that covers the same geographic area.

For all case and control children, researchers obtained demographic information, including date of birth, gender, race, and birth state, from the birth certificate or registration form that is kept in each child's permanent school record. They linked the cases and controls to the Georgia state birth certificate records, which allowed us to obtain additional information, such as each child's birth weight and gestational age and the mother's parity, age, race, and education. Of the 624 case children and 1824 control children, investigators were able to match 355 (56%) of the case and 1020 (56%) of the control children.

For children with autism, additional behavioral characteristics not collected for surveillance purposes were obtained through a secondary review of the abstracted information and were recorded in an Additional Behavioral Characteristics (ABC) data set. The review was conducted by a developmental pediatrician (Marshalyn Yeargin-Allsopp). Investigators attempted to collect additional data on family history of developmental problems, age/date of onset, pre-existing conditions, and type of developmental delay (i.e., delay, regression/plateau). Information on family history and age/date of onset was incomplete in the records and not useful for analysis.

IV. Processing of the Data

Data obtained for the purposes of MADDSP were collected through a different database than that used for this study. For the present study, a vaccination questionnaire was developed and was used by the trained abstractor to collect vaccine information and other data described previously.

The abstractors used a Microsoft Access system to collect the data. The abstractors carried laptops loaded with the MS-Access software to the data sources and directly keyed the information into the database.

Once all data were entered into the Access system, each abstractor provided a disk to the designated SAS programmer for the project who converted each abstractor's files to SAS transport files at the PC level. The transport files were then uploaded from the PC to the CDC mainframe and converted to SAS files. Edit reports were generated based on the individual abstractor's SAS files. If certain edits were to be made the abstractor went back to the original data source to verify information and made the necessary corrections. After all edits were completed, SAS files representing the data collected by each abstractor were then combined into a single SAS file. This SAS file was then linked to the Georgia birth certificate file and MADDSP data files, which are linked to the MACDP data files, from which we were able to collect information on any birth defects present in these children. The completed data file was also linked with an Additional Behavioral Characteristics (ABC) data set that was developed after the study was underway to store data that are not routinely used by MADDSP. This data set was developed to capture information on family history, whether the child had delay at less than 3 years of age, age/date of onset, whether the child had regression/plateau or general delay, and whether the child had any pre-existing conditions at less than 1 year of age.

Filters applied to the data
No filters were applied to the data other than that applied for the purposes of autism surveillance through MADDSP. Additional information on autism surveillance for MADDSP in 1996 can be found in a previously published report (Yeargin-Allsopp et al., 2003).

V. Statistical and Analytic Procedures

Because data on date/age of onset, initial parental concern, date of first autism diagnosis, or onset of regression (if present) were incomplete and not usable for analysis, the study investigators compared the distribution of ages at first MMR vaccination between case and school-matched control children. As stated in the report describing this study (DeStefano et al., 2004), this exposure comparison was established based on the assumption that MMR vaccine increases the risk of autism, which usually develops before 24 months of age, and children who are vaccinated at younger ages would have a higher risk of developing autism.

Age at exposure was examined by 1) comparing the overall distributions of age at vaccination; and 2) by three specific age-cutoffs: less than 18 months of age, less than 24 months, and less than 36 months. Less than 18 months of age

was chosen as an indicator of "on-time" vaccination according to the recommended vaccination schedule for MMR vaccine (DeStefano et al., 2004). Less than 24 months of age was chosen since that is the age by which atypical development has become apparent in most children with autism (DeStefano et al., 2004). Less than 36 months of age was chosen since that is the age by which autistic characteristics must have developed to meet DSM-IV criteria for autism (DeStefano et al., 2004). These three age cut-offs were used to examine the association between age at first MMR vaccination and autism case status for the total sample and the birth certificate sample according to gender and age, the association between age at first MMR vaccination and autism case status within select clinical subgroups of cases (i.e., regression/plateau, no pre-existing condition, with and without MR), and the association between age at first MMR vaccination and autism case status according to race, birth weight, and maternal characteristics in the birth certificate sample.

Investigators assessed the difference in demographic characteristics (i.e., birth weight, multiplicity, etc.) between case children included in the present study and those that were excluded or those for whom an immunization file in the child's school permanent record was assessed could not be located. In addition, researchers compared demographic and maternal characteristics between case and control children.

A chi square test of significance was used to compare demographic and maternal characteristics between case and control children. The overall distributions of ages at first MMR vaccination were compared using a likelihood ratio test in a conditional logistic regression model stratified by matched sets in which age at vaccination was included as a categorical variable with five age categories (DeStefano et al., 2004). Conditional logistic regression models were used to establish odds ratios (ORs) to measure the association between autism and age at first MMR vaccination divided according to the three age-cutoffs. This association was also measured in the birth certificate sample where adjusting for potential confounding variables was possible. The potential confounding variables included in the conditional logistic regression model were those with a $P < 0.20$ when evaluated independently for their association with autism.

For analyses that were stratified by birth or maternal characteristics, the matched sets were not maintained. Instead the matching factors (i.e., age, gender, and school) were included as covariates in the logistic regression models (DeStefano et al., 2004).

VI. Miscellaneous

Date and Place of Publication

The citation for this manuscript is presented below.

Destefano F, Karapurkar-Bhasin T, Thompson W, Yeargin-Allsopp M, and Boyle C. Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta. *Pediatrics* 2004; 113: 259-266.

Data Modification

Not applicable

Complete List of Data Files

There is only one data file, a fixed-width ASCII file and only be one documentation file (a *.pdf file). Both of these files will be zipped and encrypted before release.

Confidentiality Procedures

Investigators requested and received an Assurance of Confidentiality under Section 308(d) of the Public Health Service Act for MADDSP. The Assurance of Confidentiality allows for the collection of sensitive information with protection against the dangers of release of the information under the usual conditions of the Privacy Act and the Freedom of Information Act.

To further ensure the privacy of the study participants, the data set provided here has been de-identified or stripped of any individual identifiers, using primarily the safe-harbor method. According to the guidance from CDC and the U.S. Department of Health and Human Services regarding the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, the safe-harbor method is defined as the method used when a covered entity or its business associate de-identifies information by removing 18 identifiers, and the covered entity does not have actual knowledge that the remaining information can be used alone or in combination with other data to identify the subject (45 CFR § 164.514 and CDC MMWR, April 11, 2003). The relevant identifiers of the 18 variables listed under the Privacy Rule [45 CFR § 164.514] were removed from this data set. These identifiers included 1) names (child and parents/guardian); 2) all geographic subdivisions smaller than a state, including county, city, street address, precinct, zip codes, and schools/school systems; 3) all elements of dates (except year) including birth dates and vaccination dates; and 4) birth certificate numbers. The remaining identifiers of the 18 were not collected for this study.

It is important to mention that vaccination dates for all vaccines collected for this study were reduced to only the year of vaccination. However, to enable

useful analyses, variables representing age in months at the time of vaccination, and age group categories (e.g., 0-11 months, < 18 months, etc.) particular to the MMR vaccination have been provided.

Further, raw race data for individuals were removed from the data set because they were seen as potential identifiers, particularly for children with "other" race categorizations. An analytic race variable, representing white, black, or other, remains in the data set for analytic purposes.

These de-identification procedures, along with restricted access to this data set, are believed to reduce the risk of disclosure without reducing the usefulness of the data for public health practice and research.

Constraints on Data Usage

Because this is a complex study on a controversial topic and the information therein is protected under an Assurance of Confidentiality, this data set is being supplied as a "restricted access" data set. That is, only qualified researchers will be given access. Interested researchers must submit a research proposal to CDC. If the proposal is accepted, the researcher will be provided access to the data, once all parties who might have access to the data sign a Data Sharing and Use Agreement (DSA); the DSA for this study is presented in Appendix A.

Data Limitations

This data set was generated as a part of a matched case-control study. As such, specific analytical procedures must be followed for proper analysis and interpretation. At a minimum, the data should be analyzed using conditional logistic regression. Moreover, interpretations based on study data should be subject to study design considerations, described earlier. Additional limitations on data use are listed in the DSA (Appendix A).

Data Format and Usage

The data set is available as a fixed-length ASCII file. Its documentation and data dictionary will be made available as Adobe *.pdf files. All of the files to be released will be packaged and encrypted. The MMR/autism data set will be available on CD and for secure downloading from the CDC internet site (user id and password are required).

VII. Data Dictionary

The data dictionary for this data set was prepared as recommended in the *CDC/ATSDR Policy on Releasing and Sharing Data* dated April 16, 2003. It is presented in Appendix B.

VIII. References

CDC/ATSDR Policy on Releasing and Sharing Data. Manual Guide: General Administration, CDC-102, April 16, 2003. Available from http://basis1.cdc.gov/BASIS/masompb/POLICIES/POLICIES/DDD/385.

Destefano F, Karapurkar-Bhasin T, Thompson W, Yeargin-Allsopp M, and Boyle C. Age at first measles-mumps-rubella vaccination in children with autism and school-matched control subjects: a population-based study in metropolitan Atlanta. *Pediatrics* 2004; 113: 259-266.

Wakefield AJ, Murch S, Anthony A, et. al. Ileal lymphoid nodular hyperplasia, non-specific colitis and regressive developmental disorder in children. *Lancet*. 1998; 351: 637-641.

Yeargin-Allsopp M, Murphy C, Oakley G, Sikes K. A multiple-source method for studying the prevalence of developmental disabilities in children: the Metropolitan Atlanta Developmental Disabilities Study. *Pediatrics*. 1992; 89:624-630.

Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, and Murphy C. The prevalence of autism: metropolitan Atlanta. *JAMA*. 2003; 289: 49-55.

Table 1. Number of Cases and Controls in Total Sample by Select Demographic Characteristics				
Characteristic	**Cases**		**Controls**	
	N	%	N	%
Age in 1996 (yrs)				
3-5	214	34	623	34
6-10	410	66	1,201	66
Sex				
Male	500	80	1,462	80
Female	124	20	362	20
Race				
White	333	53	918	50
Black	230	37	636	35
Other	40	6	174	10
Missing	21	3	96	5
Total	624	100	1,824	100

Table 2. Frequency Count of Case and Control Children in the Birth Certificate Sample by Demographic, Maternal and Child Characteristics

Characteristic	**Cases**		**Controls**	
	N	%	N	%
Age in 1996 (y)				
3-5	127	36	376	37
6-10	228	64	644	63
Sex				
Male	282	79	809	79
Female	73	21	211	21
Race				
White	199	56	571	56
Black	137	39	384	38
Other	19	5	65	6
Missing	0	0	0	0
Maternal education (yrs)				
< 12	15	4	95	9
13-15	280	79	803	79
+16	60	17	122	12
Birth weight (g)				
0-1,499	12	3	11	1
1,500-2,499	37	10	52	5
2,500 +	306	86	957	94
Multiplicity				
Singleton	329	93	990	97
Twin +	26	7	30	3
Parity				
First born	149	42	452	44
Second or higher	204	57	560	55
Missing	2	1	8	1
Total	355	100	1,020	100

Table 3. Distribution of Cases and Controls by Age Categories for Age at First MMR Vaccination for Total Sample				
Age Category (mo)	**Cases (N=624)**		**Controls (N=1824)**	
	N	%*	N	%*
0-11	8	1	36	2
12-17	440	71	1,232	68
18-23	90	14	260	14
24-29	29	5	86	5
30-35	16	3	38	2
36 +	41	7	172	9

*Percentages were rounded to the nearest whole number.

*Table 4. Number of Children With Autism in Select Case Subgroups in **Total Sample (N=624)***	
Case Subgroup	**N**
Boys	500
Girls	124
Ages 3-5 years	214
Ages 6-10 years	410
No pre-existing condition < 1 year	390
Regression or plateau	80
With MR	376
Without MR	248

Table 5. Number of Children With Autism in Select Case Subgroups in Birth Certificate Sample (N=311)	
Case Subgroup	**N**
Boys	243
Girls	68
Ages 3-5 years	112
Ages 6-10 years	199
No pre-existing condition < 1 year	187
Regression or plateau	31
With MR	179
Without MR	132
Race	
White/other	218
Black	137
Maternal Age (yrs)	
< 35	295
35 +	60
Maternal Education (yrs)	
< 16	235
16+	120
Birthweight (g)	
< 2500	49
≥ 2500	306

Appendix A: Data Sharing and Use Agreement

Data Sharing and Use Agreement
MMR/Autism Data set

Requestor Name	_____
Affiliation	_____
Mailing Address	_____
Telephone Number	_____
EMAIL Address	_____
Method of Data Transfer (CDC to researcher)	_____

The data covered under this agreement are the data that were generated from the CDC's Measles, Mumps, and Rubella (MMR) vaccine/autism case-control study (the MMR/autism data set). This data set contains all of the variables used in the CDC analysis. This case-control study was conducted jointly by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), CDC, and the National Immunization Program (NIP), CDC. The purpose of the study was to evaluate the effect, if any, that MMR immunization had on the development of autism.

The data set being provided is a restricted access data set. That is, it is not available for unrestricted public use due to the complexity of the study design and the need on the part of the inquiring researcher to have sufficient skills to analyze the data in accordance with generally accepted scientific principles.

I, _____, (Requestor), agree to use the MMR/autism data set exactly as proposed in my research proposal, dated _____, and accepted by CDC. This proposal is attached to this agreement as Exhibit A, incorporated herein by reference. I understand that my authorized period of data use begins at 12:00 am (EST) on _____ and ends at 11:59 pm (EST) on _____. I agree not to use or access the MMR/autism data outside of the authorized period of use.

In accepting this agreement, I also agree to the following terms and conditions of data use:

1. I will not use, nor permit others to use, the data in any manner except that explicitly stated in Exhibit A.
2. I will require others in the organization that use the data to sign this agreement and will submit the signed agreements to CDC.
3. I will not attempt any linkage or combination of the MMR/autism data to any other data set for any purpose.

Data Sharing and Use Agreement
MMR/Autism Data set

4. I will not re-release, share, provide access to, or otherwise make the MMR/autism data available to any other party for any reason whatsoever. I agree to refer all requests for access to the data to the Developmental Disabilities Team Leader at CDC.
5. I agree to make no attempt to learn the identity of any person included in these data. I also agree to use the MMR/autism data for statistical reporting and analysis only.
6. I understand that CDC has de-identified the MMR/autism data set to the best of its ability, in accordance with standards for de-identification set forth in the Family Educational Rights and Privacy Act (FERPA, 20 U.S.C. § 1232g) and the Health Insurance Portability and Accountability Act (HIPAA, 45 C.F.R. Parts 160 and 164). I agree that I will not attempt, in any way, to re-identify any person included in these data.
7. I agree to make no disclosure or use of the identity of a person discovered inadvertently and will advise the Developmental Disabilities Team Leader at CDC of any such discovery in writing within two (2) business days of the date of discovery. If such a discovery is made, the information that would identify the individual will be safeguarded or destroyed as requested by CDC.
8. I also agree to the following security procedures:
    a. The MMR/autism data file is encrypted; I will only use the encrypted file and, further, I will not share passwords, encryption codes, or any other security or confidentiality maintenance information with any other party. I will not make copies of the encrypted file or any derived file(s) generated from the encrypted file, even for backup purposes.
    b. I will password protect any permanent analysis files, such as those produced by SAS or other statistical analysis package.
    c. I will treat all MMR/autism data at my desk or worksite as confidential materials and not give other persons access to it.
    d. I will keep all hard copies of analysis and data runs containing small cells, defined herein as any combination of race, ethnicity, geography, age, and/or gender that results in five (5) or fewer cases per cell, locked in my desk when they are no longer necessary to my analysis. Furthermore, I will review all printed or electronic output and delete or blackout any direct or indirect identifiers and any small cells. In addition, for public reporting of results of my analysis on the MMR/autism data, I agree not to report information on any small cells.
    e. I am responsible for obtaining IRB review of proposed research where appropriate.
9. Within seven (7) business days from the ending date of my authorized period of data use, defined above, I agree to destroy the MMR/autism encrypted data file and to notify the Developmental Disabilities Team Leader at CDC that this file has been destroyed.

Data Sharing and Use Agreement
MMR/Autism Data set

10. Within one year from the ending date of my authorized period of data use, stated above, I agree to shred all hard copies of data analysis, printouts, runs, graphs, etc. I also agree to destroy any electronic records of the same, along with any files derived from the original MMR/autism data.
11. I agree to notify the Developmental Disabilities Team Leader, in writing, if I will be changing positions within my organization or leaving my organization no later than seven (7) business days prior to my planned change or exit date. I agree not to take copies of the data or data analysis, printouts, runs, graphs, etc. with me when I leave the organization or change positions in the organization.
12. I agree not to imply or state, in either written or oral form, that interpretations based on the data are those of the original data sources (i.e., the public school system and specialty medical providers) or of CDC.
13. I agree to acknowledge, in all reports on these data, the original source of the data (i.e., the public school system and specialty medical providers).
14. I agree to provide to CDC, within one month of publication, a courtesy copy of any publications or other public disseminations of the findings of my analysis.
15. I agree to indemnify and hold CDC, its employees, agents, assigns, and contractors (and their subcontractors and vendors) harmless for any damages, actual or consequential, that may arise from installation of the encrypted data onto any computers.
16. I agree that CDC has the right to conduct on-site audits, without prior notice, of my use of the MMR/autism data set to verify compliance with the terms and conditions of this Agreement. I agree to provide any information deemed relevant to these audits to CDC personnel.
17. I understand that the following federal laws may pertain to this data**;** that these laws allow for criminal and civil penalties for disclosure and violation of confidentiality**;** that I am solely responsible for compliance with these and other applicable federal laws**;** and that I will also investigate and comply with any relevant state laws that might pertain to this data. The applicable laws include but are not limited to:

    a. Human subjects common rule
       45 CFR § 46
    b. Assurances of Confidentiality
       Section 308(d) of the
       Public Health Service Act
       42 USC 242 m(d)
    c. Privacy Act
       5 USC § 552a; 45 CFR § 5b

Any failure by the Requestor to abide by terms of this Agreement constitutes a breach of this Agreement and may result in CDC obtaining any remedy authorized by law including, but not limited to, specific performance and cancellation or recision of the

Data Sharing and Use Agreement
MMR/Autism Data set

Agreement, which will require the Requestor to return all data obtained hereunder and the destruction, under the supervision of CDC, of all copies of data in the Requestor's possession, as well as in the possession of any of the Requestor's employees, agents, assigns, and subcontractors. In any action brought by CDC under this Agreement in which CDC prevails, CDC shall be entitled to its attorney's fees and court costs. This provision applies to the extent permitted by Federal law.

SIGNATURE:_____ TITLE: _____

ORGANIZATION:

_____

Subscribed and sworn before me **(Affix Notary Stamp)**

This _____ day of _____, 20___

Notary Public, State of _____ _____

Notary Public Signature

Appendix B: Data Dictionary

Data Dictionary
Study of Age at First MMR Vaccination and Autism

This data set is an analysis data set. The data set represents the number of cases and controls that were used in final analysis, after all exclusions were applied. See data documentation guide for description of exclusions.

The data file variables included in the data set is presented in this dictionary in alphabetical order by variable name. For each data item, a general description, rationale, valid codes, formats, and meanings are provided. The at-a-glance header for each of the variables includes the variable name, data type, format, length, and valid codes. All data items that represent personal identifying information or could be used to personally identify an individual in the study have been removed from the current data set. The data items to be removed from the data set were primarily determined based on the Privacy Rule. Some of the data items that were removed from this data set include any individual's name, address, city, county, zip codes, all elements of dates including birth dates and vaccination dates, and birth certificate numbers. Further, data variables that were likely to contain small number of children in particular data cells were excluded. For example, M_race, the variable for maternal race on the Georgia birth certificate file was removed from the data set because of the likelihood to identify a child in one of the "Other" race categories such as American Indian, Chinese, Japanese, Hawaiian, Cajun/Creole, and Filipino. Categorical variables that were used in analysis and were derived from these original variables remained on the data set.

An at-a-glance summary table of all of the variables included in the data file can be found on the first few pages of the data dictionary for quick reference.

The following are a few abbreviations that are referenced through out the dictionary.

Abbreviation	Full Name
MADDSP	Metropolitan Atlanta Developmental Disabilities Surveillance Program
MACDP	Metropolitan Atlanta Congenital Defects Program
ASD	Autism Spectrum Disorders
CP	Cerebral Palsy
MR	Mental retardation
DTP	Diptheria-Pertussis-Tetanus vaccination
MMR	Measles-Mumps-Rubella vaccination
IPV	Inactivated Polio Vaccine
OPV	Oral Polio Vaccine
HIB	Haemophilus Influenzae B Vaccine
HEPB	Hepatitis B vaccine

Data Dictionary
Study of Age at First MMR Vaccination and Autism

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
AGE1996	Age of child during 1996 study year	Numeric	8	001	--	--
AGE1998	Age of child at time of MMR abstraction	Numeric	8	009	--	--
AGE2_5	Children ages 2 to 5 years	Numeric	8	017	1 0	Yes No
AGE6_8	Children ages 6 to 8 years	Numeric	8	025	1 0	Yes No
AGE96CAT	Age group categories of children -3 age groups	Numeric	8	033	1 2 3	2-5 years 6-8 years 9-12 years
AGE9_12	Children ages 9 to 12 years	Numeric	8	041	1 0	Yes No
AGECAT96	Age group categories of children-2 age groups	Numeric	8	049	1 2	2-5 years => 6 years
ANYVAC17	Any MMR Vaccine through 17 months	Numeric	8	057	1 0	Yes No
ANYVAC23	Any MMR Vaccine through 23 months	Numeric	8	065	1 0	Yes No
ANYVAC35	Any MMR Vaccine through 35 months	Numeric	8	073	1 0	Yes No
AUCASEDF	MADDSP autism case definition	Character	1	081	1	Case
BCSAMP	Birth certificate sample	Numeric	8	082	1 0	Yes No
BD_1YR	Diagnosis of a birth defect by 1 year of age	Numeric	8	090	1 0	Yes No
BIRTH2ND	Child born 2nd or higher order birth	Numeric	8	098	1 0	Yes No
BORDMISS	Missing birth order data	Numeric	8	106	1 0	Yes No
BTHMULT	MMR birth multiplicity analytic variable	Numeric	8	114	1 2	Singleton Multiple birth
BTHSOUR	Child abstracted at both school and non-school sources for MADDSP	Character	1	122	Y N	Yes No
BTYPMISS	Missing birth multiplicity data from birth certificate	Numeric	8	123	1 0	Yes No
BWTCAT	MMR analytic birth weight categories	Numeric	8	131	1 2 3	0-1,499 g 1,500-2,499 g ≥ 2,500 g
BWTMISS	Missing birth weight data	Numeric	8	139	1	Yes

Data Dictionary
Study of Age at First MMR Vaccination and Autism

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
	from birth certificate				0	No
BYR	Child's birth year	Character	8	147	--	--
CASEMMR	MMR/Autism case-control status	Numeric	8	155	1 0	Case Control
CASENUM	Child's identification number for MMR study, positions 1 through 6	Character	7	163	--	--
CNTLNUM	Child's identification number position 7	Character	7	170	--	--
CPCASEDF	MADDSP cerebral palsy case definition	Character	1	177	1	Case
CP_1YR	Diagnosed with cerebral palsy by 1 year of age	Numeric	8	178	1 0	Yes No
DDBYONE	Developmental delay by 1 year of age	Character	1	186	1 2 3	Yes No Suspected
DELAY1	MMR analytic variable for presence of delay by 1 year of age	Numeric	8	187	1 0	Yes No
DEVLBL	Type of developmental presentation: Regression/plateau or developmental delay	Character	1	195	1 2	Delay Regression/Plateau
DOBMISS	Missing date of birth information	Numeric	8	196	1 0	Yes No
DTP1MON	Age at 1st dose of DTP vaccine in months	Numeric	8	204	--	--
DTP2MON	Age at 2nd dose of DTP vaccine in months	Numeric	8	212	--	--
DTP3MON	Age at 3rd dose of DTP vaccine in months	Numeric	8	220	--	--
DTP4MON	Age at 4th dose of DTP vaccine in months	Numeric	8	228	--	--
DTP5MON	Age at 5th dose of DTP vaccine in months	Numeric	8	236	--	--
DTP6MON	Age at 6th dose of DTP vaccine in months	Numeric	8	244	--	--
DTPAGE2	Number of DTP doses by age 2	Numeric	8	252	--	--
EPILDUM	MMR analytic variable for presence of epilepsy	Character	1	260	1 0	Yes No

Data Dictionary
Study of Age at First MMR Vaccination and Autism

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
EXCODE1	Code for 1st vaccine exemption	Character	2	261	1 2 8	Religious Medical Other
EXCODE2	Code for 2nd vaccine exemption	Character	2	263	1 2 8	Religious Medical Other
EXCODE3	Code for 3rd vaccine exemption	Character	2	265	1 2 8	Religious Medical Other
FIRSTMEA	Age in months of first measles containing vaccination	Numeric	8	267	--	--
FIRSTVAC	Age at receipt of first any MMR vaccination	Numeric	8	275	--	--
HICASEDF	MADDSP case definition for hearing loss	Character	1	283	1	Case
HI_1YR	Diagnosis of hearing loss by age 1 year	Numeric	8	284	1 0	Yes No
IDNUM	MMR study identification number	Character	7	292	--	--
IMMFILE	Presence of immunization form in child's file	Character	1	299	1 2	Yes No
IMMFMISS	Immunization form missing in child's file	Numeric	8	300	1 0	Yes No
IPV1MON	Age at 1st dose of IPV vaccine in months	Numeric	8	308	--	--
IPV2MON	Age at 2nd dose of IPV vaccine in months	Numeric	8	316	--	--
IPV3MON	Age at 3rd dose of IPV vaccine in months	Numeric	8	324	--	--
IPV4MON	Age at 4th dose of IPV vaccine in months	Numeric	8	332	--	--
MAGEMISS	Missing maternal age information	Numeric	8	340	1 0	Yes No
MATAGE	MMR maternal age categories	Numeric	8	348	1 2 3	< 20 yrs 20-34 yrs ≥ 35 yrs
MATEDUC	MMR maternal education categories	Numeric	8	356	1 2 3	≤ 12 yrs 13-15 yrs ≥ 16 yrs
MATRACE	MMR maternal race categories	Numeric	8	364	1 2	White Black

Data Dictionary
Study of Age at First MMR Vaccination and Autism

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
					3	Other
MEA1CAT1	First receipt of any measles vaccine - age categories in months	Numeric	8	372	1 2 3 4 5 6	0-11 mos 12-17 mos 18-23 mos 24-29 mos 30-35 mos ≥ 36 mos
MEA1MON	Age in months at 1st measles single antigen vaccine	Numeric	8	380	--	--
MEA2MON	Age in months at 2nd measles single antigen vaccine	Numeric	8	388	--	--
MEAVAC17	Receipt of any measles vaccination through 17 months	Numeric	8	396	1 0	Yes No
MEAVAC23	Receipt of any measles vaccination through 23 months	Numeric	8	404	1 0	Yes No
MEAVAC35	Receipt of any measles vaccination through 35 months	Numeric	8	412	1 0	Yes No
MEDUMISS	Missing maternal education information from the birth certificate	Numeric	8	420	1 0	Yes No
MMR1CAT1	First receipt of MMR vaccination- age categories	Numeric	8	428	1 2 3 4 5 6	0-11 mos 12-17 mos 18-23 mos 24-29 mos 30-35 mos ≥ 36 mos
MMR1MON	Age in months at 1st MMR vaccine	Numeric	8	436	--	--
MMR2MON	Age in months at 2nd MMR vaccine	Numeric	8	444	--	--
MMR3MON	Age in months at 3rd MMR vaccine	Numeric	8	452	--	--
MMRFIRST	Age in months at first MMR vaccination	Numeric	8	460	--	--
MMRVAC17	Receipt of MMR vaccination through 17 months	Numeric	8	468	1 0	Yes No
MMRVAC23	Receipt of MMR	Numeric	8	476	1	Yes

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
	vaccination through 23 months				0	No
MMRVAC35	Receipt of MMR vaccination through 35 months	Numeric	8	484	1 0	Yes No
MRACMISS	Missing maternal race information	Numeric	8	492	1 0	Yes No
MRCASED1	MMR analytic variable – children who met MADDSP autism and MR case definition for MADDSP	Numeric	8	500	1 0	Yes No
MRCASEDF	MADDSP case definition for MR	Character	1	508	1	Case
MR_1YR	Diagnosis of mental retardation by age 1 year	Numeric	8	509	1 0	Yes No
MUM1MON	Age in months at 1st dose of mumps vaccine	Numeric	8	517	--	--
MUM2MON	Age in months at 2nd dose of mumps vaccine	Numeric	8	525	--	--
M_AGEC	Mother age from C_DOB M_DOB variables from birth certificate 80ON	Numeric	8	533	--	--
M_EDUC	Mother education in years from birth certificate 80ON	Character	2	541	00 13 14 15 16 17 18	None 1 yr college 2 yr college 3 yr college 4 yr college 5 + yr college Unknown
NSCHOOL	Child abstracted at non-school source only	Character	1	543	Y N	Yes No
OPV1MON	Age in months at 1st dose of OPV vaccine	Numeric	8	544	--	--
OPV2MON	Age in months at 2nd dose of OPV vaccine	Numeric	8	552	--	--
OPV3MON	Age in months at 3rd dose of OPV vaccine	Numeric	8	560	--	--
OPV4MON	Age in months at 4th dose of OPV vaccine	Numeric	8	568	--	--
OPV5MON	Age in months at 5th dose of OPV vaccine	Numeric	8	576	--	--
OPV6MON	Age in months at 6th dose	Numeric	8	584	--	--

Data Dictionary
Study of Age at First MMR Vaccination and Autism

Variable Name	Label	Data Type	Length	Starting Position	Codes	Values
	of OPV vaccine					
PRECON	Presence of a pre-existing condition by age 1 year	Character	1	592	1 2 3	Yes No Suspected
PREVDIAG	MMR analytic variable for presence of previous diagnosis	Numeric	8	593	1 0	Yes No
RACECAT	MMR race categories for total sample	Numeric	8	601	1 2 3	White Black Other
RACEMISS	Missing race information from all race sources for total sample	Numeric	8	609	1 0	Yes No
REGRESS1	MMR analytic variable for presence of regressive development	Numeric	8	617	1 0	Yes No
RUB1MON	Age in months of 1st dose of rubella vaccine	Numeric	8	625	--	--
RUB2MON	Age in months of 2nd dose of rubella vaccine	Numeric	8	633	--	--
SCHSOUR	Child abstracted at school source only for MADDSP	Character	1	641	Y N	Yes No
SEX	MMR gender variable	Character	1	642	1 2	Male Female
SEXMALE	MMR analytic variable-gender male	Numeric	8	643	1 0	Yes No
SEXMISS	Missing gender information	Numeric	8	651	1 0	Yes No
VAC1CAT1	First receipt of any measles, mumps, or rubella vaccine – age categories	Numeric	8	659	1 2 3 4 5 6	0-11 mos 12-17 mos 18-23 mos 24-29 mos 30-35 mos ≥ 36 mos
VICASEDF	MADDSP analysis variable for vision impairment case definition	Character	1	667	1	Case
VI_1YR	Vision impairment by age 1 year	Numeric	8	668	1 0	Yes No

Variable Name	Label	Data Type	Length
AGE1996	Age of child during 1996 study year	Numeric	8

Description

Represents the age of the child in the study population during 1996, the study year for MADDSP's Autism Surveillance Program. Behavioral information was reviewed and abstracted on children who either had a previous diagnosis of autism or a select school exceptionality code or were 3 to 10 years of age in 1996.

Rationale

N/A

Codes and Valid Values
Age is provided in years.

Variable Name	Label	Data Type	Length
AGE1998	Age of child at time of MMR abstraction	Numeric	8

Description

Represents the age of the child during the year when abstraction for the MADDSP Autism Surveillance Program began. MADDSP is an ongoing retrospective surveillance program that monitors the occurrence of select developmental disabilities.

Rationale
N/A

Codes and Valid Values
Age is provided in years.

Variable Name	Label	Data Type	Length
AGE2_5	Children ages 2 to 5 years	Numeric	8

Description

Represents the analytic variable used to indicate whether or not a child was between 2 and 5 years of age in 1996. This variable was created based on the variable, AGE96CAT, described below.

Rationale

Analytic variables representing age categories were created to study the association of receipt of first MMR vaccination in certain age groups. Further, Yes/No variables of participation in certain age groups were established for the analytic models examining the association of first MMR vaccination by certain age groups.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
AGE6_8	Children ages 6 to 8 years	Numeric	8

Description

Represents the analytic variable used to indicate whether or not a child was between 6 and 8 years of age in 1996. This variable was created based on the variable, AGE96CAT, described below.

Rationale

Analytic variables representing age categories were created to study the association of receipt of first MMR vaccination in certain age groups. Further, Yes/No variables of participation in certain age groups were established for the analytic models examining the association of first MMR vaccination by certain age groups.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
AGE96CAT	Age group categories of children-3 age groups	Numeric	8

Description

Represents age categories broken out into three groups. Age categories were derived from the ages of children in 1996, variable AGE1996.

Rationale

These three age categories were created to establish analytic age category variables for the logistic regression models. The analytic variables (AGE2_5, AGE6_8, AGE9_12) indicate whether a child was or was not in one of these age groups in 1996.

Codes and Valid Values

1 2 to 5 years
2 6 to 8 years
3 9-12 years

Variable Name	Label	Data Type	Length
AGE9_12	Children ages 9 to 12 years	Numeric	8

Description

Represents the analytic variable used to indicate whether or not a child was between 9 and 12 years of age in 1996. This variable was created based on the variable, AGE96CAT, described below.

Rationale

Analytic variables representing age categories were created to study the association of receipt of first MMR vaccination in certain age groups. Further, Yes/No variables of participation in certain age groups were established for the analytic models examining the association of first MMR vaccination by certain age groups.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
AGECAT96	Age group categories of children-2 age groups	Numeric	8

Description

Represents age categories broken out into 2 age groups. The age categories were derived from the ages of the children in 1996, variable AGE1996.

Rationale

N/A

Codes and Valid Values

1 2 to 5 years
2 6 years and older

Variable Name	Label	Data Type	Length
ANYVAC17	Any MMR Vaccine through 17 months	Numeric	8

Description

An analytic variable indicating whether or not a child had any of the measles, mumps, or rubella single antigen vaccines through 17 months of age. The variable was created from the VAC1CAT1 variable described below which categories children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any of the measles, mumps, or rubella single antigen vaccines. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received any one of these vaccines before 18 months of age, one of the age-cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
ANYVAC23	Any MMR Vaccine through 23 months	Numeric	8

Description

An analytic variable indicating whether or not a child had any of the measles, mumps, or rubella single antigen vaccines through 23 months of age. The variable was created from

the VAC1CAT1 variable described below which categories children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any of the measles, mumps, or rubella single antigen vaccines. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received any one of these vaccines before 24 months of age, one of the age-cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
ANYVAC35	Any MMR Vaccine through 35 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had any of the measles, mumps, or rubella single antigen vaccines through 35 months of age. The variable was created from the VAC1CAT1 variable described below which categorizes children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any of the measles, mumps, or rubella single antigen vaccines. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received any one of these vaccines before 36 months of age, one of the age-cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length

AUCASEDF	MADDSP autism case definition	Character	1

Description

Represents whether a child met the MADDSP case definition for autism during the 1996 study year. All children classified as MMR cases had to have met this case definition.

Rationale
N/A

Codes and Valid Values

1 Case

Variable Name	Label	Data Type	Length
BCSAMP	Birth certificate sample	Numeric	8

Description

Represents the children with autism for whom we had birth certificate information. In analysis of the birth certificate sample it is important to use this variable to restrict the cases to those born in Georgia.

Rationale

For the purpose of this study, children with autism were linked to the GA birth certificate file to obtain additional information on select birth and maternal characteristics. The additional information obtained from the birth certificates allowed for adjustment of potential confounders.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BD_1YR	Diagnosis of a birth defect by 1 year of age	Numeric	8

Description

Represents those children with autism who had a diagnosis of a birth defect by 1 year of age. The records of children with autism who were positively linked with the

Metropolitan Atlanta Birth Defects Program (MACDP) allowed investigators to make this determination.

Rationale

One of the aims of this study was to examine whether or not there was an increased risk for autism in select subgroups. One of the subgroups examined was children who did not have any indication of developmental delay or a pre-existing condition by 1 year of age. In order to create that subgroup, all children with a diagnosis of a developmental disability or birth defect had to be excluded from that group.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BIRTH2ND	Child born 2nd or higher order birth	Numeric	8

Description

This parity variable indicates whether or not a child was second born in the family. This variable was derived through a syntax using the following birth certificate variables: H_PLIVE, H_LIVEND, H_LIVENL, H_LNDL, H_LNDM, H_LNLL, H_LNLM, AND H_LBORDR.

Rationale

This variable was created to create birth order categories to be used in the logistic regression models and to characterize the children in the sample.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BORDMISS	Missing birth order data	Numeric	8

Description

This variable indicates whether or not children who were born in Georgia were missing birth order information from the birth certificate file.

Rationale

Understanding the magnitude of missing birth order data was important to assess whether this variable was useful to characterize the children with a Georgia birth certificate and further, to assess whether birth order could be used as a covariate in the logistic regression models.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BTHMULT	MMR birth multiplicity analytic variable	Numeric	8

Description

This is an analytic variable that was created from the birth certificate variable for birth multiplicity. Represents whether a child was born from a singleton birth or a twin or higher order multiple birth.

Rationale

While the original birth certificate variables contain more refined stratifications for birth multiplicity (single, twin, triplet, other multiple birth, or unknown), for our analytic purposes it was decided to collapse twins, triplets, and other multiples into a single category of higher order multiple births.

Codes and Valid Values

1 Singletons
2 Higher order multiple births

Variable Name	Label	Data Type	Length
BTHSOUR	Child abstracted at both school and non-school sources for MADDSP	Character	1

Description

This variable indicates which children with autism had behavioral information abstracted from both school and non-school sources for MADDSP.

Rationale

To assess what programs children with autism participated in and to examine whether how they were identified had any impact on the results of the study, the study investigators looked at whether children with autism were abstracted at school and non-school sources (both sources), school sources only, or non-school sources only.

Codes and Valid Values

Y Yes
N No

Variable Name	Label	Data Type	Length
BTYPMISS	Missing birth multiplicity data from birth certificate	Numeric	8

Description

This variable was created to represent children in the study sample who were born in Georgia who were missing birth multiplicity data from the Georgia birth certificate file.

Rationale

Understanding the magnitude of missing birth multiplicity data was important to assess whether this variable was useful to characterize the sample of children with a Georgia birth certificate and further, to assess whether birth multiplicity could be used as a covariate in the logistic regression models.

Code and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BWTCAT	MMR analytic birth weight categories	Numeric	8

Description

This variable is an analytic variable used in the study to represent birth weight categories that were used in analysis. The birth weight data is represented in grams. This variable was derived from birth weight variables from the Georgia birth certificate file.

Rationale

For the purpose of this study, birth weight categorizations were necessary to examine the association between age at first MMR vaccination and autism case status according to birth weight.

Codes and Valid Values

1 < 1,500 grams
2 1,500-2,499 grams
3 ≥ 2,500 grams

Variable Name	Label	Data Type	Length
BWTMISS	Missing birth weight data from birth certificate	Numeric	8

Description

Represents the children in the study sample who were born in Georgia who were missing birth weight information from the Georgia birth certificate files.

Rationale

Understanding the magnitude of missing birth weight data was important to assess whether this variable was useful to characterize the sample of children with a Georgia birth certificate and further, to assess whether birth weight could be used as a covariate in the logistic regression models.

Code and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
BYR	Child's birth year	Character	8

Description

Represents the birth year for each child in the study sample.

Rationale

Birth date information was necessary to establish the child's age in months at the time the first dose of the MMR vaccination or any other vaccines was given. While full birthdates were used to establish the age of the child at the time of vaccine administration, the child's birth year was the only portion of the entire date that was retained for this data set to ensure the study child's privacy.

Codes and Valid Values

Birth year was recorded in the format, YYYY. Example: 1993

Codes and Valid Values

Y Yes
N No

Variable Name	Label	Data Type	Length
CASEMMR	MMR/Autism case-control status	Numeric	8

Description

Represents case-control status for the children in the study population.

Rationale

This variable allows the analyst to distinguish between cases and controls for the study and allows for creation of matched sets.

Codes and Valid Values

1 Case
0 Control

Variable Name	Label	Data Type	Length
CASENUM	Child's identification number for MMR study, positions 1 through 6	Character	7

Description

Represents the six digit identification number for the children in the study sample. Cases and their respective matched controls share this same six digit base number.

Rationale

This variable helps identify matched case-control sets for the purpose of matched analysis.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
CNTLNUM	Child's identification number position 7	Character	7

Description

Represents the six digit base identification number (CASENUM) plus a seventh digit which distinguishes the cases from the controls. The seventh digit for the cases ends in '0' while the seventh digit for the controls is represented by a '1', '2', or '3'. The seventh digit for controls is represented by a '1', '2', or '3' to represent the control-to-case ratio that was used for this study, 3:1.

Rationale

The variable can be used to distinguish cases from controls.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
CPCASEDF	MADDSP cerebral palsy case definition	Character	1

Description

Represents whether a child met the MADDSP case definition for cerebral palsy during the 1996 study year.

Rationale

This variable allows one to see whether a child had cerebral palsy as a co-existing condition

Codes and Valid Values

1 Case

Variable Name	Label	Data Type	Length
CP_1YR	Diagnosed with cerebral palsy by 1 year of age	Numeric	8

Description

Represents the children with autism who had a diagnosis of cerebral palsy by 1 year of age.

Rationale

The children with a diagnosis of cerebral palsy by 1 year of age were children that were excluded from the subgroup, children without a pre-existing condition that was used in analyses for this study. As defined in the manuscript for this study and the data documentation, children without a pre-existing condition were those children who did not have a major birth defect, a co-occurring disability, or a major perinatal or postnatal insult (i.e., infection, injury) that could have contributed to developmental delays.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
DDBYONE	Developmental delay by 1 year of age	Character	1

Description

Represents the children with autism who had indication of developmental delays indicated in their behavioral record.

Rationale

It was important to know which children had a developmental delay before 1 year of age since the delays found in this group were not likely to be due to the MMR vaccine, typically given for the first time after 1 year of age. These children were excluded from the subgroup of children without any indication of developmental delay before 12 months of age. As defined in the manuscript and the data documentation, children without developmental delay before 1 year of age were children who did not lack any speech at

appropriate ages, including cooing or babbling, and were socially responsive in the first year of life (e.g., cuddling, appropriate eye contact, responding to parent's voices).

Codes and Valid Values

1 Yes
2 No
3 Suspected

Variable Name	Label	Data Type	Length
DELAY1	MMR analytic variable for presence of delay, pre-existing condition, including co-existing disability, by 1 year of age	Numeric	8

Description

This is an analytic variable that represents children who had a developmental delay or a pre-existing condition by 1 year of age. This includes children who had a co-existing disability by 1 year of age. This variable is derived from the following variables: DDBYONE, PRECON, MR_1YR, CP_1YR, HI1_YR, VI1_YR, and BD1_YR.

Rationale

This variable was created since children without a pre-existing condition and developmental delays by 1 year of age were grouped together for analytic purposes. Excluding children based on the outcome of this variable allows for the creation of that subgroup.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
DEVLBL	Type of developmental presentation: Regression/Plateau or developmental delay	Char	1

Description

Represents the type of developmental presentation such as regression or plateau and developmental delay. The variable categorizes the children with autism into these two

groups based on the abstracted information that was reviewed by the developmental pediatrician.

Rationale

One of the aims of the study was to examine association of the age at first MMR vaccination in select subgroups that may be at increased risk for autism from the vaccine. One of the subgroups of interest was children with regression or plateau in development. Children with regression or plateau were grouped together for analytic purposes. This variable allowed investigators to distinguish children with regression/plateau from those with developmental delay.

Codes and Valid Values

1 Developmental Delay
2 Regression/plateau

Variable Name	Label	Data Type	Length
DOBMISS	Missing date of birth information	Numeric	8

Description

Represents children with missing birth date information.

Rationale

It was important to know which children were missing birth date information because the age at first MMR vaccination could not be determined for these children. Age at first MMR vaccination or any measles vaccination (measles, mumps, or rubella) was determined based on the child's birth date and the administration date of the first dose of the MMR vaccination or any measles vaccination.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
DTP1MON	Age at 1st dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age in months at the first dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTP2MON	Age at 2nd dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age in months at the second dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTP3MON	Age at 3rd dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age at the third dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the third dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended per the ACIP recommendation and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received was collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTP4MON	Age at 4th dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age in months at the fourth dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the fourth dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended per the ACIP recommendation and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTP5MON	Age at 5th dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age in months at the fifth dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the fifth dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended per the ACIP recommendation and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received was collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTP6MON	Age at 6th dose of DTP vaccine in months	Numeric	8

Description

Represents the child's age in months at the sixth dose of the DTP vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the sixth dose of the DTP vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended per the ACIP recommendation and that was recorded in the child's immunization form was collected for this study. All DTP vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
DTPAGE2	Number of DTP doses by age 2	Numeric	8

Description

The variable represents the number of DTP doses a child received by the age of 2 years when atypical development is likely to have occurred. This variable was created based on the ages the children received the DTP vaccinations.

Rationale

The number of DTP doses by age 2 years was calculated in case investigators ever wanted to examine the pattern of administration of this vaccine between cases and controls. This variable was used to determine which children did not have a DTP vaccination by age 2 which was one of the criteria used to establish which children had

incomplete vaccination records. Children were excluded from the analysis if they did not have at least one DTP vaccination by age 2 years or at least one MMR vaccination at any age.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
EPILDUM	MMR analytic variable for presence of epilepsy	Character	1

Description

This is an analysis variable that was created to indicate whether children with autism had epilepsy or not.

Rationale

This variable was created to describe the study population in terms of the co-existing disabilities that may be present among children with autism.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
EXCODE1	Code for 1st vaccine exemption	Character	2

Description

Represents the code for the first vaccine exemption. The code could illustrate whether a child received a religious or medical exemption.

Rationale

While the type of exemption was not necessary for the purpose of this study, the presence of any type of exemption played a role in determining the reason a child may not have a complete immunization record. Children with an exemption were not excluded from the study.

Codes and Valid Values

1 Religious exemption
2 Medical exemption
8 Unknown

Variable Name	Label	Data Type	Length
EXCODE2	Code for 2nd vaccine exemption	Character	2

Description

Represents the code for the second vaccine exemption. The code could illustrate whether a child received a religious or medical exemption.

Rationale

While the type of exemption was not necessary for the purpose of this study, the presence of any type of exemption played a role in determining the reason a child may not have a complete immunization record. Children with an exemption were not excluded from the study.

Codes and Valid Values

1 Religious exemption
2 Medical exemption
8 Unknown

Variable Name	Label	Data Type	Length
EXCODE3	Code for 3rd vaccine exemption	Character	2

Description

Represents the code for the third vaccine exemption. The code could illustrate whether a child received a religious or medical exemption.

Rationale

While the type of exemption was not necessary for the purpose of this study, the presence of any type of exemption played a role in determining the reason a child may not have a complete immunization record. Children with an exemption were not excluded from the study.

Codes and Valid Values

1 Religious exemption
2 Medical exemption
8 Unknown

Variable Name	Label	Data Type	Length
FIRSTMEA	Age in months at first measles containing vaccination	Numeric	8

Description

Represents the age of the child in months when the first measles containing vaccine was administered.

Rationale

There were a few children in the study sample who received the single antigen measles vaccine. This variable accounts for any errors in the chronological order of the measles containing vaccines that were administered so that the first dose of the measles containing vaccine is in fact the first dose. For instance, MEA1MON which was calculated from the child's date of birth and date of what was recorded as the first dose of the measles vaccine may not have actually been the first dose of the vaccine if one were to look at the full dates of each of the vaccines that were recorded on the immunization form. Code was created to account for any recording or abstraction errors.

Code and Valid Values

N/A

Variable Name	Label	Data Type	Length
FIRSTVAC	Age at receipt of first any MMR vaccination	Numeric	8

Description

Represents the age of the child in the study sample in months at receipt of any of the measles, mumps, or rubella single antigen vaccines.

Rationale

Represents the age of the first dose of any of the measles, mumps, or rubella vaccines after taking into account the chronological order that the child received them in.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
HICASEDF	MADDSP case definition for hearing loss	Character	1

Description

Represents whether a child met the MADDSP case definition for hearing loss during the 1996 study year.

Rationale
Allows investigators to assess whether a child had a co-existing disability of hearing loss

Codes and Valid Values

1 Case

Variable Name	Label	Data Type	Length
HI_1YR	Diagnosis of hearing loss by age 1 year	Numeric	8

Description

Represents the children with autism who had a diagnosis of hearing loss by 1 year of age.

Rationale

The children with a diagnosis of hearing loss by 1 year of age were excluded from the subgroup of children without a pre-existing condition that was used in analyses for this study. As defined in the manuscript for this study and the data documentation, children without a pre-existing condition were those children who did not have a major birth defect, a co-occurring disability, or a major perinatal or postnatal insult (i.e., infection, injury) that could have contributed to developmental delays.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
IDNUM	MMR study identification number	Character	7

Description

Represents the child's study identification number

Rationale

The identification number is used to distinguish one child from another and to also distinguish cases from controls.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
IMMFILE	Presence of immunization form in child's file	Character	1

Description

This variable indicates whether a child had an immunization form present in his/her permanent school record file.

Rationale

It was important to keep track of who had an immunization form on file so that investigators could determine who had valid immunization information.

Codes and Valid Values

1 Yes
2 No

Variable Name	Label	Data Type	Length
IMMFMISS	Immunization form missing in child's file	Numeric	8

Description

Represents those children who were missing an immunization form from their school records.

Rationale

For analytic purposes, it was important to keep track of those children who were missing an immunization form so that they could be appropriately excluded from the study analysis.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
IPV1MON	Age at 1st dose of IPV vaccine in months	Numeric	8

Description

Represents the child's age in months at the first dose of the IPVvaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the IPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All IPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
IPV2MON	Age at 2st dose of IPV vaccine in months	Numeric	8

Description

Represents the child's age in months at the second dose of the IPVvaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the IPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All IPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
IPV3MON	Age at 3rd dose of IPV vaccine in months	Numeric	8

Description

Represents the child's age in months at the third dose of the IPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the third dose of the IPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All IPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
IPV4MON	Age at 4th dose of IPV vaccine in months	Numeric	8

Description

Represents the child's age in months at the fourth dose of the IPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the fourth dose of the IPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All IPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MAGEMISS	Missing maternal age information	Numeric	8

Description

Represents the children who were born in Georgia and who were missing maternal age information from the Georgia birth certificate file.

Rationale

Because maternal age was a covariate used in the conditional logistic regression models, it was important to know which children were missing this information so that they could be appropriately excluded from analysis.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MATAGE	MMR maternal age categories	Numeric	8

Description

Represents the analytic variable used to represent maternal age categories. This variable was derived from the M_AGEC variable from the Georgia birth certificate file.

Rationale

Maternal age categories that are commonly used in the scientific epidemiologic research were used to assess the association of the age at first MMR vaccination according to maternal age. Further, maternal age was a confounding factor that was adjusted for in the main and subgroup analyses of the birth certificate sample.

Codes and Valid Values

1 < 20 years
2 20-34 years
3 ≥ 35 years

Variable Name	Label	Data Type	Length
MATEDUC	MMR maternal education categories	Numeric	8

Description

Represents the analytic variable used to represent maternal education categories. This variable was derived from the M_EDUC variable from the Georgia birth certificate file.

Rationale

Maternal education categories were created to assess the association of the age at first MMR vaccination according to maternal education. Maternal education was a potential confounding factor that was adjusted for in the main and subgroup analyses of the birth certificate sample.

Codes and Valid Values

1 ≤ 12 years
2 13-15 years
3 ≥ 16 years

Variable Name	Label	Data Type	Length
MATRACE	MMR maternal race categories	Numeric	8

Description

Represents the analytic variable for maternal race categories. It was created from the M_RACE variable from the Georgia birth certificate file. This variable was the primary race variable used in logistic regression analysis of the birth certificate sample, while other sources of race were used for the total sample (See RACECAT).

Rationale

For analytic purposes, children were categorized into race designations of White, Black, and Other. Because the percentage of children who are Other/Pacific Islander, American Indian, Chinese, Japanese, Hawaiian, Cajun/Creole, and Filipino are small, they were grouped together in an "Other" race category. Children of Hispanic origin were grouped in either the White or Black categories as either White Hispanics or Black Hispanics.

Codes and Valid Values

1 White

2 Black
3 Other

Variable Name	Label	Data Type	Length
MEA1CAT1	First receipt of any measles vaccine - age categories in months	Numeric	8

Description

Represents refined age categories (6), in months, for the first receipt of any measles-containing vaccine. This variable was derived from the variable, FIRSTMEA.

Rationale

These refined age categories were established so that investigators could examine the overall distribution of age at first measles containing vaccination using more narrow age categories.

Codes and Valid Values

1 0-11 months
2 12-17 months
3 18-23 months
4 24-29 months
5 30-34 months
6 ≥ 36 months

Variable Name	Label	Data Type	Length
MEA1MON	Age in months at first measles single antigen vaccine	Numeric	8

Description

Represents the child's age in months at the first dose of the measles single antigen vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the measles vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MEA2MON	Age in months at second measles single antigen vaccine in months	Numeric	8

Description

Represents the child's age at the first dose of the IPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the IPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MEAVAC17	Receipt of any measles vaccination through 17 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had any of the measles containing vaccinations through 17 months of age. The variable was created from the MEA1CAT1 variable described above which categories children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any measles containing vaccinations through 17 months of age. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received a measles containing vaccination before 18 months of age, one of the age cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MEAVAC23	Receipt of any measles vaccination through 23 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had any of the measles containing vaccinations through 23 months of age. The variable was created from the MEA1CAT1 variable described above which categories children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any measles containing vaccinations through 23 months of age. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received a measles containing vaccination before 24 months of age, one of the age cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MEAVAC35	Receipt of any measles vaccine through 35 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had any of the measles containing vaccinations through 35 months of age. The variable was created from the MEA1CAT1 variable described previously which categorizes children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had any measles containing vaccinations through 35 months of age. The study investigators examined the pattern of receipt of vaccination of these specific vaccines in instances where the child did not receive the combined MMR vaccine. This is a Yes/No variable that was created to represent if a case or control received a measles containing vaccination before 36 months of age, one of the age-cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MEDUMISS	Missing maternal education information from the birth certificate file	Numeric	8

Description

Represents the children who were born in Georgia and who were missing maternal education information from the Georgia birth certificate file.

Rationale

It was important to know which children who were born in Georgia were missing maternal education since maternal education was a covariate in the logistic regression analysis among the birth certificate sample. Children in the birth certificate sample who were missing this information were excluded from the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MMR1CAT1	First receipt of MMR vaccination: age categories in months	Numeric	8

Description

Represents refined age group categories (6) for the first receipt of the MMR vaccination as indicated in the child's immunization form. This variable was created from the variable, MMRFIRST, described below.

Rationale

These refined age categories were established so that investigators could examine the overall distribution of age at first MMR vaccination using more narrow age categories.

Codes and Valid Values

1 0-11 months
2 12-17 months
3 18-23 months
4 24-29 months
5 30-34 months
6 ≥ 36 months

Variable Name	Label	Data Type	Length
MMR1MON	Age at 1st MMR vaccine in months	Numeric	8

Description

Represents the child's age in months at the first dose of the MMR vaccine in months. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the MMR vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MMR2MON	Age at 2nd MMR vaccine in months	Numeric	8

Description

Represents the child's age in months at the second dose of the MMR vaccine. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the MMR vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MMR3MON	Age at 3rd MMR vaccine in months	Numeric	8

Description

Represents the child's age in months at the third dose of the MMR vaccine in months. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the third dose of the MMR vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MMRFIRST	Age of 1st MMR vaccination in months	Numeric	8

Description

Represents the age of the child in months when the first dose of the MMR vaccination was administered.

Rationale

This variable was created to take into account any errors that may exist in the chronological order of the MMR vaccinations that were recorded in the immunization form. Represents the age of the child at the first dose of the MMR vaccination. The MMR1MON variable, which typically represents the first dose of the MMR vaccine may not have actually been the age of the child at the first dose. As with the FIRSTMEA

variable, this code was created to take into account any recording or abstraction errors that may have occurred.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MMRVAC17	Receipt of MMR vaccination through 17 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had an MMR vaccination through 17 months of age. The variable was created from the MMR1CAT1 variable described previously which categorizes children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had an MMR vaccination through 17 months of age. This is a Yes/No variable that was created to represent if a case or control received an MMR vaccination before 18 months of age, one of the age cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MMRVAC23	Receipt of MMR vaccination through 23 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had an MMR vaccination through 23 months of age. The variable was created from the MMR1CAT1 variable described previously, which categorizes children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had an MMR vaccination through 23 months of age. This is a Yes/No variable that was created to represent if a case or control received an MMR vaccination before 24 months of age, one of the age cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MMRVAC35	Receipt of MMR vaccination through 35 months	Numeric	8

Description

Represents an analytic variable indicating whether or not a child had an MMR vaccination through 35 months of age. The variable was created from the MMR1CAT1 variable described previously which categorizes children into more refined or narrow age groups.

Rationale

This analytic variable was created to indicate whether a child had an MMR vaccination through 35 months of age. This is a Yes/No variable that was created to represent if a case or control received an MMR vaccination before 36 months of age, one of the age cut-offs used in the study.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MRACMISS	Missing maternal race information	Numeric	8

Description

Represents the children who were born in Georgia and who were missing maternal race (M_RACE) information from the Georgia birth certificate file.

Rationale

For the adjusted analyses that were conducted among the birth certificate sample, it was important to know which children were missing race information, because maternal race was a covariate in the adjusted analyses. Children who were missing this information from the birth certificate file were excluded from the adjusted analyses.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MRCASED1	MMR analytic variable- children who met MADDSP case definition for autism and MR case definition for MADDSP	Numeric	8

Description

Represents those children with autism who also met the MADDSP case definition for mental retardation. This variable was derived from the MADDSP variable for MR, MRCASEDF.

Rationale

This variable allowed investigators to create subgroups of children with and without mental retardation. These subgroups were used in analyses to measure the association of the first age of MMR vaccination in select subgroups that may be at increased risk for autism.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MRCASEDF	MADDSP case definition for MR	Character	1

Description

Represents whether a child met the MADDSP case definition for mental retardation during the 1996 study year.

Rationale
This variable allows investigators to assess whether a child had a co-existing disability of mental retardation.

Codes and Valid Values

1 Case

Variable Name	Label	Data Type	Length
MR_1YR	Diagnosis of mental retardation by age 1 year	Numeric	8

Description

Represents the children with autism who had a diagnosis of mental retardation by 1 year of age.

Rationale

The children with a diagnosis of mental retardation by 1 year of age were children that were excluded from the subgroup, children without a pre-existing condition that was used in analyses for this study. As defined in the manuscript and data documentation for this study, children without a pre-existing condition were those children who did not have a major birth defect, a co-occurring disability, or a major perinatal or postnatal insult (i.e., infection, injury) that could have contributed to developmental delays.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
MUM1MON	Age at 1st dose of mumps vaccine in months	Numeric	8

Description

Represents the age of the child in months at the first dose of the mumps single antigen vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the mumps vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
MUM2MON	Age at 2nd dose of mumps vaccine in months	Numeric	8

Description

Represents the child's age in months at the second dose of the mumps single antigen vaccine. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the mumps vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
M_AGEC	Mother age from C_DOB M_DOB variables from birth certificate 80ON	Numeric	8

Description

This variable is the original variable from the Georgia birth certificate file that represents the mother's age at the time of the child's birth. It is calculated from the mother's date of birth and the child's date of birth. This variable is available for births beginning in 1980.

Rationale

This variable allowed investigators to establish maternal age categories for the analytic purposes.

Codes and Valid Values
N/A

Variable Name	Label	Data Type	Length
M_EDUC	Mother education in years from birth certificate 80ON	Character	2

Description

This variable is the original variable from the Georgia birth certificate file that represents the mother's education at the time of the child's birth. This variable is available on the Georgia birth certificate file from 1980 and onwards.

Rationale

The data in this field allowed investigators to establish maternal education categories for analysis in this study.

Codes and Valid Values

00	None
13	1 yr college
14	2 yr college
15	3 yr college
16	4 yr college
17	5 + yr college
18	Unknown

Variable Name	Label	Data Type	Length
NSCHOOL	Child abstracted at non-school source only	Character	1

Description

This variable was created to represent children with autism who were identified through MADDSP from non-school sources only.

Rationale

To assess what programs children with autism participated in and to examine how they were identified had any impact on the results of the study, the study investigators looked

at whether children with autism were abstracted at school and non-school sources (both sources), school sources only, or non-school sources only.

Codes and Valid Values

Y Yes
N No

Variable Name	Label	Data Type	Length
OPV1MON	Age in months at 1st dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the first dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
OPV2MON	Age in months at 2nd dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the second dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
OPV3MON	Age in months at 3rd dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the third dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the third dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
OPV4MON	Age in months at 4th dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the fourth dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the fourth dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
OPV5MON	Age in months at 5th dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the fifth dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the fifth dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
OPV6MON	Age in months at 6th dose of OPV vaccine	Numeric	8

Description

Represents the child's age in months at the sixth dose of the OPV vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the sixth dose of the OPV vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recommended by the ACIP and that was recorded in the child's immunization form was collected for this study. All OPV vaccinations a child may have received were collected.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
PRECON	Presence of a pre-existing condition by age 1 year	Character	1

Description

Represents the children with autism who had a pre-existing condition that could have led to developmental delays. Pre-existing conditions include major birth defects, traumatic brain injury, and central nervous system infections.

Rationale

Children without a pre-existing condition were a subgroup of children with autism in which specific analyses were conducted to measure an association of age at first MMR vaccination in subgroups of children that may be at increased risk for autism. For analytic purposes children without a pre-existing condition and children without known developmental delays by 1 year of age were grouped into a single category. In order to create these subgroups it was important to know which children had a pre-existing condition.

Codes and Valid Values

1 Yes
2 No
3 Suspected

Variable Name	Label	Data Type	Length
PREVDIAG	MMR analytic variable for presence of previous diagnosis	Numeric	8

Description

This is an analytic variable that represents children with autism who had a previous diagnosis of ASD as indicated in an evaluation that was reviewed and abstracted by MADDSP.

Rationale

It was originally created to assess if there was a difference in the results if the sample of children with autism were limited to those children with a previous diagnosis.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length

RACECAT	MMR race categories for total sample	Numeric	8

Description

Represents the race categories of Black, White, and Other that were established for the total sample (those born in and outside of Georgia) based on the available sources for race. It is important to note that race was collected for the MMR study from the birth certificate record or the registration form in the child's school record; however, this information was often incomplete particularly for those children not born in Georgia. However, for children identified through MADDSP, the case children for the MMR study, it was possible to obtain race information from additional sources of information that were abstracted for surveillance purposes. In order to obtain race information on the children in the total sample that was as complete as possible, an algorithm was established to create these race categories. The RACECAT variable was created based on the race information found in the data fields for the variables RACE (original variable for the MMR study), M_RACE, and C_RACE. Because additional sources for obtaining race information were available for children identified through MADDSP, children with autism were less likely to be missing race information compared to the school-matched control children. The RACECAT variable was used to determine the proportion of children in the White, Black, and Other race categories for descriptive purposes in Table 1 of the manuscript (DeStefano et al., 2004) and the data documentation.

Rationale

Because roughly one third of the children in the study sample were not born in Georgia, it was important to create a race category variable that represented the total sample. Broad race categories of White, Black, and Other were established because the percentage of children who are American Indian, Chinese, Japanese, Hawaiian, Cajun/Creole, and Filipino was small and thus these categories were grouped together in an "Other" race category. Children of Hispanic origin were grouped in either the White or Black categories as either White Hispanics or Black Hispanics.

Codes and Valid Values

1 White
2 Black
3 Other

Variable Name	Label	Data Type	Length
RACEMISS	Missing race information from all race sources for total sample	Numeric	8

Description

Represents children from the total sample who were missing race information from any of the allowable sources for race for the total sample (see description for RACECAT).

Rationale

This variable allows investigators to determine which children were missing race information based on any of the sources for race for the total sample.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
REGRESS1	MMR analytic variable for presence of regressive development	Numeric	8

Description

This analytic variable represents the children with autism who had loss of previously acquired skills or regression in development or children whose developmental did not progress (plateau in development). Children with regression or plateau were grouped together for analytic purposes.

Rationale

As recommended by the IOM in 2001, this study aimed to examine the association of the age at first MMR vaccination in subgroups of children with autism who may have been at increased risk for developing autism from the MMR vaccination. The subgroups of children with regression or plateau in development were of particular interest.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
RUB1MON	Age at 1st dose of rubella vaccine in months	Numeric	8

Description

Represents the child's age in months at the first dose of the rubella single antigen vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the first dose of the rubella vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
RUB2MON	Age of 2nd dose of rubella vaccine in months	Numeric	8

Description

Represents the child's age in months at the second dose of the rubella single antigen vaccination. The age in months was calculated from the child's date of birth (MM/DD/YYYY) and the administration date of the second dose of the rubella vaccination (MM/DD/YYYY).

Rationale

All vaccine information that was recorded on the child's immunization form was collected for this study.

Codes and Valid Values

N/A

Variable Name	Label	Data Type	Length
SCHSOUR	Child abstracted at school source only for MADDSP	Character	1

Description

Represents children with autism who were identified through MADDSP from school sources only.

Rationale

To assess what programs children with autism participated in and to examine whether how they were identified had any impact on the results of the study, the investigators looked at whether children with autism were abstracted at school and non-school sources (both sources), school sources only, or non-school sources only.

Codes and Valid Values

Y Yes
N No

Variable Name	Label	Data Type	Length
SEX	MMR gender variable	Character	1

Description

The original gender variable collected for the present study.

Rationale

Demographic information on children in the study sample was collected.

Codes and Valid Values

1 Male
2 Female

Variable Name	Label	Data Type	Length
SEXMALE	MMR analytic variable - gender male	Numeric	8

Description

An analytic variable to indicate whether or not a child in the study sample was male.

Rationale

This variable was created for analytic purposes.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
SEXMISS	Missing gender information	Numeric	8

Description

Represents the children in the study sample who were missing gender information.

Rationale

The association of age of first MMR vaccination by the three age cutoffs was examined in different demographic subgroups of which gender was one. Further, in the unconditional logistic regression analyses, gender was included as a covariate in the model. Therefore, it was necessary to know which children were missing this information.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
VAC1CAT1	First receipt of any measles, mumps, or rubella vaccine – age categories	Numeric	8

Description

Represents refined age categories (6), in months, for the first receipt of any measles, mumps, or rubella single antigen vaccine. This variable was derived from the variable, FIRSTVAC.

Rationale

These refined age categories were established so that investigators could examine the overall distribution of age at first measles, mumps, or rubella single antigen vaccination using more narrow age categories.

Codes and Valid Values

1 0-11 months
2 12-17 months
3 18-23 months
4 24-29 months

5 30-34 months
6 ≥ 36 months

Variable Name	Label	Data Type	Length
VI_1YR	Vision impairment by age 1 year	Numeric	8

Description

Represents the children with autism who had a diagnosis of vision impairment by 1 year of age.

Rationale

The children with a diagnosis of vision impairment by 1 year of age were excluded from the subgroup of children without a pre-existing condition that was used in analyses for this study. As defined in the manuscript for this study and the data documentation, children without a pre-existing condition were those children who did not have a major birth defect, a co-occurring disability, or a major perinatal or postnatal insult (i.e., infection, injury) that could have contributed to developmental delays.

Codes and Valid Values

1 Yes
0 No

Variable Name	Label	Data Type	Length
VICASEDF	MADDSP analysis variable for vision impairment case definition	Character	1

Description

Represents the children with autism who also met the MADDSP case definition for vision impairment.

Rationale

Many children with autism have a co-existing developmental disability. This variable allows investigators to quantify the number of children with autism and vision impairment.

Codes and Valid Values

1 Case