

- [Hoffmann, Candice \(CDC/OID/NCEZID\)](#)

Thank you for your help. I appreciate it.

Best,
Katie

From: "Hoffmann, Candice (CDC/OID/NCEZID)" <hqx5@cdc.gov>
To: Katie Weisman
Sent: Tuesday, February 11, 2014 2:13 PM
Subject: RE: New DSM-5 study questions

Here's the response from Dr. Maenner:

Thanks again for your interest in our work. We realize that many people are concerned about changes to service provisions that might stem from changes to the ASD criteria. CDC is currently conducting studies that hopefully will provide insight into how the new criteria has impacted coverage. In our recent paper, the objective was to examine the impact on the surveillance classification of ASD—which includes some children that had clear symptoms of ASD but did not have evidence of ever being diagnosed. Thus, we believe the data from the next DSM-5 analysis will have more relevance to questions about diagnostic practices in the community.

To answer your question about the children who had some ASD symptoms but did not meet ADDM ASD case status, there were 473 in 2006 and 547 in 2008 (for a total of 1020). We have not yet performed this analysis for earlier years.

Best,
Candice

From: Katie Weisman
Sent: Friday, February 07, 2014 1:32 PM
To: Hoffmann, Candice (CDC/OID/NCEZID)
Subject: Re: New DSM-5 study questions

Thank you.

Katie

From: "Hoffmann, Candice (CDC/OID/NCEZID)" <hqx5@cdc.gov>
To: Katie Weisman
Sent: Friday, February 7, 2014 9:58 AM
Subject: RE: New DSM-5 study questions

I'm checking on this and will get back to you soon.

From: Katie Weisman
Sent: Thursday, February 06, 2014 6:59 PM
To: Hoffmann, Candice (CDC/OID/NCEZID)
Subject: Re: New DSM-5 study questions

Dear Ms. Hoffmann,

Thanks very much for getting back to me. I'm sure that you understand how concerned our community is about the impact of the new criteria. I have 16 year old triplets - all on the spectrum - and I have run a local support group for parents for over a decade now. I have heard too many stories of denied services to be unconcerned.

Is it possible to get an answer to my question about how those 1020 children were distributed over the two years and whether there were similar cohorts in previous reporting years? It partially addresses the question of how changes in diagnostic practices have changed over time - particularly as the higher-functioning kids are concerned. I would think that information would be readily available.

Best,
Katie Weisman

From: "Hoffmann, Candice (CDC/OID/NCEZID)" <hqx5@cdc.gov>
To: "Katie Weisman"
Sent: Thursday, February 6, 2014 3:55 PM
Subject: RE: New DSM-5 study questions

Dear Ms. Weisman,

I'm a press officer in CDC's National Center on Birth Defects and Developmental Disabilities. Thanks for reaching out to us, and I'm sorry for the delay in getting back to you. Below is Dr. Maenner's response to your questions. Please let me know if you have any follow-up questions.

Thank you for your interest in our article and for your questions. We understand your concerns in terms of how the new DSM-5 criteria for autism spectrum disorder (ASD) might impact service eligibility; however, this study was not designed to address this issue. In our study, we analyzed data collected through CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. Specifically, we looked at information from health and education records from 2006-2008. DSM-5 was not in use during this time frame. As doctors and other clinicians start using the DSM-5 criteria, they might diagnose ASD using new or revised tools or they might document symptoms differently. These changes in everyday community practice could offset the DSM-5's effect on ASD prevalence estimates. We are working on additional studies to better understand the 'real-world' impact of the DSM-5 ASD criteria.

Thank you for your question about the 1020 children in our study that did not meet ADDM Network ASD case definition. Very few of these children had a diagnosis or suspicion of PDD-NOS or ASD documented in their records. These children did have documentation of some behaviors consistent with ASD—often accumulating over several years and multiple evaluations—but those documented behaviors were not sufficient to meet the standardized ADDM ASD case definition. Hypothetically, if this group of children who did not meet ADDM ASD case definition were included, it would not change the overall trends over time or site-to-site differences in ASD prevalence.

The ADDM Network clinician reviewers determine whether children meet the ADDM Network ASD case status. They do not diagnose children with alternate conditions if they do not meet the ASD criteria. Children that do not meet the ADDM Network ASD case status were given a variety of diagnostic labels by community professionals: ADHD, speech or language delays, intellectual disabilities, and other mood or behavioral disorders. At the time we did the study, we did not believe that we could reliably capture the criteria for Social Communication Disorder (SCD) using the behavioral information systematically collected by the ADDM Network, but we plan to revisit this question once we have a better understanding of how children are diagnosed with SCD.

There were 304 children that met DSM-5 criteria but did not meet current ADDM ASD case status. In this analysis, this group represents the upper limit on potential cases “gained” with the new criteria. We included these 304 as part of the prevalence exercise, but these children were not reviewed by clinicians to determine DSM-5 ASD case status. It is likely that many would be classified as having another disorder—as they were for the current (DSM-IV based) ADDM Network methods. As we describe in the article, it would seem that the number of cases “lost” would outnumber the cases “gained” under DSM-5 criteria, but the present-day ratio of cases lost vs gained remains to be seen.

Thanks again for your interest in our work.

Candice Burns Hoffmann

Press Officer (on detail)

National Centers on Birth Defects and Developmental Disabilities

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From: Katie Weisman

Sent: Monday, January 27, 2014 2:37 PM

To: Maenner, Matthew J. (CDC/ONDIEH/NCBDDD)

Subject: New DSM-5 study questions

Dear Dr. Maenner,

I am reading, with interest, your new study from JAMA Psychiatry. I spent an extensive amount of time in 2012 and 2013 reading all the literature about the development of the DSM-5 criteria for ASDs and wrote an analysis for parents in May of 2013 which I presented at the Autism One Conference in Chicago (attached). I had several phone calls with Dr. Swedo about the community's concerns about the impact of the new criteria and spoke to Dr. Volkmar about his impressions as well. Unfortunately, it looks like the concerns are starting to pan out. I projected at least a 20% drop based on all the studies I read and your new work reports a similar drop.

I am starting to hear reports in NYS that insurance companies are requiring children to be re-evaluated using the DSM-5 criteria to determine continued eligibility for coverage of therapies. So far, we have not been able to update our insurance legislation to include both definitions. As a parent of triplets on the spectrum and chair of a local parent support group, this is a hot topic right now. I appreciate your team doing this analysis as a starting point.

I do have a few questions regarding the details of the paper if you could possibly answer them:

1) I had not seen in any previous ADDM reports that there were PDD-NOS eligible children who were not included as cases (the 1020). Is it possible for you to give me a breakdown of how many of those children were in each of the 2006 and 2008 surveillance cohorts either in

aggregate and/or by state? Since the PDD-NOS children were disproportionately affected in most of the DSM-5 studies I read, I am wondering how their exclusion might have affected the prevalence numbers and whether there was a trend over time towards more of these "loose ASD" cases in total or in specific states. This might also explain some of the wide state-to-state disparities. Also, were there similar PDD-NOS cases excluded from any of the previous surveillance years or was this only done in 2006 and 2008?

2) For those PDD-NOS children who were excluded, what were the typical "other diagnoses" that the clinicians felt were more appropriate? I have huge concerns about children with ASD being shunted into the new Social Communication Disorder category - for which there is no existing research base and therefore no evidence to support needed services. We had a huge battle over "evidence-based" language in passing our NYS insurance bill. Also, did you do any analysis of whether some of the 2006 and 2008 surveillance cohorts would have met criteria for SCD?

3) The 304 cases, of the 1020, that did meet criteria for DSM-5 ASD, represented 30% of those children. The field trials reported picking up new cases that met DSM-5 criteria, but not DSM-IVTR criteria but the fallout was pretty evenly distributed between the three old diagnoses. Do you have an opinion on the likely percentage of "substitution" effect of the new criteria (new cases picked up vs. dropped)?

I would appreciate your help, as I am planning to do follow-up pieces on the DSM-5 impact as it evolves.

Thanks, very much.

Best Regards,
Katie Weisman
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