

**DataSpeak**  
**“Bringing ADHD Epidemiology to States:  
What Could State-Based Estimates Mean for Your State?”**  
**September 7, 2011**

**Presentation**

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Good afternoon. Welcome to today’s program bringing attention deficit hyperactivity disorder epidemiology to states. What could state-based estimates mean for your state? I’m Michael Kogan, and I’m the Director of HRSA’s Maternal and Child Health Bureau’s Office of Epidemiology, Policy, and Evaluation. The DataSpeak series is sponsored through the offices of Maternal and Child Health Information Resource Center.

Today, we’re delighted to have with us speakers representing both Federal and state involvement in ADHD epidemiology. Our first speaker today will be Susanna Visser, who’s the lead epidemiologist for the Child Development Study Team within the National Center on Birth Defects and Developmental Disabilities, Epicenters for Disease Control and Prevention. She’ll provide an overview of the epidemiological trends in childhood ADHD over time using data from the National Survey of Children’s Health.

Our next two presenters will provide information on how their states have used these state-based estimates from the National Survey of Children’s Health to advance initiatives in the mental and behavioral health of children. Our two speakers are Charlie Biss, the Children’s Mental Health Director for the Vermont Department of Mental Health; and Dr. Patsy Carter, the Director of Children’s Clinical Services in Missouri’s Department of Mental Health.

Now, before we begin, I’d like to introduce Sara Lifsey, the Moderator for today’s program. Sara, it’s all yours.

**Sara Lifsey- DataSpeak Moderator, Maternal and Child Health Information Resource Center**

Thank you, Michael. First, I’d like to welcome our presenters and everyone who is the audience today. Thank you for joining us. Before we begin our presentation, I just have some brief, technical guidance for you all.

First, I’d like to call your attention to the DataSpeak website, which we hope you’ll visit after today’s program. There you’ll find resources on today’s topic, including some of the resources that our speakers will highlight in today’s presentation. Also on the website, you can find archives of all of the DataSpeak programs going back to the year 2000. The slide on your screen shows some of the most recent programs that are available and the address you can use to access them.

I’d also like to point out that you’re able to download today’s PowerPoint presentation directly from the screen that you’re looking at right now. Over on the left-hand side is a little box that says “Downloads.” If you click on the presentation to highlight it, and click “save to my computer,” and follow the simple instructions on the screen, you can save a copy of today’s presentation.

Finally, please know that your phone line will be muted during the presentation. At the completion of the program, we'll be having a question and answer session, and we'll provide instructions for asking questions over the telephone at that time. If you'd like to post a question online, you can do so at any time during the program, and we'll be answering them towards the end of the program. You can use the questions box. It's on the lower, right-hand side of your screen. It says "Q&A." Just type your question in the box next to the arrow and hit "enter."

Now, I would like to turn to our first speaker, Susanna Visser, who will talk about the increase in ADHD prevalence and medication treatment over time at both the national and the state level. Susanna?

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Thank you very much for having me and for the introduction. ... and begin by presenting a summary of descriptive epidemiology of ADHD based on analyses of the National Survey of Children's Health Data.

The learning objectives for this presentation include the following: We'll be able to identify the current prevalence of ADHD among American children; report the percent increase and national rates of ADHD since the first wave of these surveys in 2003; we'll identify the states in which the rates of ADHD medication use have increased over the past four years, and talk about some potential reasons for these increases. Finally, we'll have a discussion of how these data could be meaningful and useful for states.

These analyses are grounded in the public health model, which I present here, adopted from the model published by Mercy et al in 1993. The public health model really begins with defining the problem, and then moving to identify risk and protective factors, developing and testing prevention strategies, and then attempting to assure widespread adoption. This isn't meant to be a linear model. It's meant to be very dynamic and iterative, and optimally you'd have evaluation built in at every level.

For those of you who are not as familiar with attention deficit hyperactivity disorder, it's the most common neurobehavioral disorder of childhood, and it's characterized by pervasive inattention with or without hyperactivity or impulsivity. And the cornerstone, really, to this disorder is that there is functional impairment as a function of these symptoms, and you have to have this impairment in at least two domains. That could include peer functioning, functioning at home, or functioning at school.

And ADHD symptoms can be developmentally appropriate. A four-year-old, for example, it's perfectly normal for that four-year-old to have symptoms of inattention or hyperactivity, but as the child ages and moves into school age we should see those symptoms start to remit and become more manageable over time. When that doesn't happen, that's when we start to wonder about the symptoms reaching a threshold of a disorder. And again, without that functional impairment, those symptoms don't translate to a disorder.

So there are a lot of myths and misconceptions about ADHD because of this lack of understanding of how significant impairment needs to be before it reaches the level of a disorder. And partially because of this, ADHD has been the subject of considerable public debate and controversy. There's both concerns about ADHD being over diagnosed and over treated, but there are also concerns that those who have the disorder and are most at risk are not being assessed for the disorder or may not have access to care to receive diagnosis and treatment.

To combat this, CDC funds and supports the National Resource Center for ADHD, which is a program of CHADD, and it's an evidence-based source for information about ADHD. It includes a Spanish and English call center and a website, [www.help4adhd.org](http://www.help4adhd.org), and it presents evidence-based information that's

overseen by a professional advisory board that checks this information to make sure that we're combating some of the myths and misconceptions about ADHD.

One of the core functions of public health is to monitor the health of the nation, and we certainly can do this through population-based studies of ADHD in the field. A number of studies were conducted in the 1990s and into the 2010 time frame, and several of them are included here.

You'll see that each of these studies is either direct assessment of children or used some sort of record review; medical, school, or psychiatric record review to ascertain what the prevalence of ADHD was in communities. And although these were very popular between about 1997 and 2005, the frequency with which these population-based studies has started to dwindle, and it makes it very difficult to monitor the rates of ADHD prevalence in the United States.

So in order to continue to be able to monitor this very important condition over time, we've turned to our national surveys. I've listed a few here that are conducted by CDC's National Center for Health Statistics.

The first is an in-person household interview, the National Health Interview Survey, which includes about 8,000 to 13,000 sample children per year, and it is parent report for the sample child questions and indicators.

The National Health and Nutrition Examination Survey is a direct interview coupled with an examination of about 5,000 people per year, some of whom are children. However, it's not conducted annually and it's difficult. In order to generate estimates, you have to combine years to get enough samples to generate prevalence estimates.

Then we have a mechanism really, the State and Local Area Integrated Telephone Survey, and this mechanism is used to administer two very important surveys; one of which I'll really focus on today. The first is the National Survey of Children with Special Health Care Needs, and the second is the National Survey of Children's Health. Both are sponsored and directed by MCHB at HRSA, and the product officer is Dr. Michael Kogan, who's on the call with us. These surveys are very important for monitoring the prevalence of ADHD over time.

We have used the National Health Interview Survey, which is the first survey that I discussed, to look at prevalence over time. This figure is presented in a report that was published just this past month by Dr. Akinbami from the National Center for Health Statistics, and it shows you the rates of ADHD over time from 1998 to 2009. And you can see that there is a steady increase over time.

However, it is not possible to easily look at state-based estimates using the National Health Interview Survey. And for that, we turn to the National Survey of Children's Health, which is really uniquely positioned to be able to address questions of state-based estimates and variability across estimates among children. It's a random digit dial survey of parents in the United States, and it was conducted for the first time in 2003 and then administered again in 2007. It's actually in the field now in 2011 through 2012.

The special design feature of the National Survey of Children's Health includes a state stratification variable, which means that they're sampling within states. They get up to approximately 1,750 surveys conducted per state, and that allows for national and state-based estimates for specific higher prevalence conditions including ADHD. In total, there's about 100,000 surveys conducted for each survey ways, and that varies from year to year, slightly.

This is the ADHD content that's covered in the National Survey of Children's Health. In 2003 there were two questions, "Has a doctor or health professional ever told you that your child had ADHD?" And if the parent answers in the affirmative, then they're asked, "Is your child currently taking medication for ADHD?"

This changed somewhat in 2007 when two additional questions were added. So after the parent responded as to whether or not they had ever been told by a health professional that their child had ADHD, if they said yes, they were asked is the child currently had ADHD. Then if they said yes that their child has current ADHD, they were asked if they were currently taking medication for ADHD and then also to rate the child's ADHD as either mild, moderate, or severe.

So this fiscal approach that we took for the current presentation and report was that we took the 73,123 parent interviews for children 4 to 17 years of age, and we generated weighted estimates of ADHD in 2007 overall and by demographics for the indices that we had available to us. Then we statistically compared the rates of medication across ADHD severity groups, and then compared rates of ADHD across the two surveys between 2003 and 2007. And we did this at the national level, but then also by demographic subgroups and by states. And we'll be focusing really on the national and state comparisons today.

The majority of the results I'll be presenting in the next series of slides here are included in the report that's referenced at the bottom, and is also available in your supplementary materials on the DataSpeak website.

So to begin, the rates of parent reported ADHD diagnosis in 2007 among those 4 to 17 years of age was 9.5%. Among those who are 4 to 17 who had a current diagnosis, we found a rate of 7.2%, and then 4.8% of children 4 to 17 had a current diagnosis and were also currently medicated.

When we look on the right of the slide at the pie chart, we see the proportional distribution of these groups. And you'll see that about half of those who had ever been given a diagnosis of ADHD had a current diagnosis and were currently taking medication. And the other half were split pretty evenly between having a diagnosis, but it wasn't current; or having a current diagnosis, but not currently taking medication.

When you project these estimates out to the national population of children, we find that the total percentage of children who had ever received a diagnosis represents about 5.4 million children. And then about 4.1 million children had a current diagnosis; 2.7 million children were currently taking medication for the disorder.

We also saw that rates of medication increased with severity of the disorder based on parent report. So you see that approximately 56% of children who had mild ADHD were taking medication, and almost 86% were taking medication among those who had severe ADHD.

Moving to the state-based estimates, this map reveals the rates of ADHD ... into different groups so that you can see that the darker states have the higher rates of ADHD across the nation. You'll see that there's a concentration of higher rates in the southeast, and it decreases as you move westward and south. So in the southwest we saw the lowest rates overall of ADHD. The highest rates among the states were in North Carolina, Alabama, Louisiana, and Delaware. Those four states have the highest rates of ADHD, and exceeded 14% of children 4 to 17 years of age within that state.

Turning to medication, you see the same sort of pattern with concentration of higher prevalence of ADHD medication in the southeast, and decreasing as we move towards the west and the south. The highest

rates for ADHD medication among children who currently had ADHD included North Carolina, Louisiana, and West Virginia.

This is another way to look at the state-based rates, and you'll see that what I've done is I've ordered these states in terms of ADHD prevalence, and then looked to see, this is current prevalence, among those what is the proportional rate of current medication treatment among those who have a current diagnosis. And what you'll see is that there's quite a variability in terms of the proportion of children within each state that were taking medication among those who had a current diagnosis. The highest proportional rates of medications were found in Tennessee, Iowa, and Rhode Island.

Now we'll turn and look at the changes over time. Overall, the rate of having ever been told that the child had ADHD increased from 7.8% in 2003 to 9.5% in 2007, and that represented a 22% increase in approximately four years. That also reflects approximately one million more children nationally with a history of an ADHD diagnosis.

Here we see that we saw an increase in every region of the United States except for the west where that magnitude of difference did not reach statistical significance.

Here we present the 12 states that saw significant increases between 2003 and 2007 in having ever been told that the child had ADHD. And you can see these 12 states here. We have the individual rates for the remaining states in blue.

Here are the same 12 states, and you can see what the rates were in 2003 as compared to 2007. And so there is a several percentage point increase for each state. In addition to these 12 states, we have statistical trends for Nebraska, Alabama, and Maryland.

So what can we say about rates of medication treatment over time? As I mentioned earlier, we had to be somewhat careful in doing these comparisons because the denominator changed. We used to ask the medication question of those who had ever had an ADHD diagnosis, and now in the most recent survey in 2007, we asked that question only of those who currently had an ADHD diagnosis.

But what we can cautiously say is that in 2003 the rate of ADHD medication for those 4 to 17 years of age was 4.3% of American children. And that represented about 56% of children who had ever had an ADHD diagnosis, or approximately 2.5 million children

In 2007, the rate was 4.8% for 4 to 17 year olds who were taking ADHD medication, and that was about two thirds of children with a current ADHD diagnosis. That reflects approximately 2.7 million children 4 to 17 years of age.

So the cautious conclusion here is that the absolute number of children taking ADHD medication appears to have increased between 2003 and 2007, although we can't do a direct statistical comparison because of that change in the denominator.

So here I present a summary of the findings. First that rates of parent reported ADHD diagnosis increased by 22% in four years reflecting one million more children who have the diagnosis in 2007 as compared to 2003. The rates certainly vary by state, and 12 states have significant increases in prevalence. And notably, not one state had a significant decrease in ADHD prevalence over the two time frames.

By 2007, we estimate that nearly 1 in 10 school age children had a diagnosis of ADHD and approximately two thirds of those with a current diagnosis were taking medication, representing approximately 2.7 million children.

Rates of medication seem to increase with ADHD severity, as expected, and North Carolina and Louisiana had the highest rates of ADHD overall. Nevada had the lowest rates of ADHD, and Tennessee, Iowa, and Rhode Island had the largest proportional rates of medication among the states.

So I'd like to point out a couple of discussion points here in the form of frequently asked questions that I get when I'm presenting these data. The first are, "Are parent reported data reliable?" And this has also come to me as a question, "This is based on parent report not real diagnostic information, right?"

And I would say to that that there are two elements to that question. The first is the question of the data's reliability. And when we look at reliability in terms of a psychometric question, we're looking to see if we're measuring the same thing over time. And a good indication of that is that your estimates trend very smoothly over time. And we certainly see that for the exact same question in our National Health Interview Survey, where we're seeing those estimates reported back to us in an annual fashion, and there's a very, very smooth trend to those statistics. So they appear very reliable.

The second part of that question is really are parent reported data valid? And although we can't conclude that because we haven't done that validity study to do a diagnostic evaluation of children who have had a parent report of ADHD, we do have several elements that support that these data are probably valid.

The first is that estimates of prevalence appear to be within a reasonable range of the other population-based studies, some of which I referenced earlier in the presentation. And also estimates of prevalence seem to track in a predictable fashion in terms of relative magnitude to other conditions, other neurobehavioral conditions. For example, the rate of TS, current Turret's Syndrome, is approximately 2 per 1,000 in the National Survey of Children's Health. It's 11 per 1,000 for Autism, and 72 per 1,000 for current ADHD. And that's generally the relative prevalence that we would expect.

And finally, and this isn't a small point, a parent report of ADHD represents nomination of the lived experience within families. And if a parent tells us that their child has ADHD or if they've been told that the child has ADHD, then this probably reflects a lived experience of what's happening in that family and it's important to us from a public health perspective.

So are there really more cases of ADHD or are we just noticing more problematic behaviors than we used to? And I have a couple of possible explanations with increasing rates here that address that very issue.

The first is that we may be seeing increases in prevalence due to stepped-up development screening effort. And when you do more screening, you're hoping to find more symptoms, and we find more symptoms that should lead to the question of whether or not there should be more diagnosis. So that's part of it.

The second is greater awareness. We have several awareness campaigns that are very active right now, and improved awareness among health care practitioners and parents should lead to more questions within the waiting room and within clinical practice that could lead to more diagnosis.

There have also been less stigmas surrounding ADHD, as we've been able to dispel some of the myths and misconceptions about ADHD, and with less stigma there probably is a greater likelihood that parents will pursue a diagnosis for their child. And there's definitely been a better portfolio of treatment options in recent years with long-acting medications and non-stimulant formulations, better behavioral therapies, and better coordination of treatment across health care providers and school health professionals.

Finally we can't exclude the possibility that there are simply more cases of ADHD out there, and that could be due to known causes of ADHD, which would include lead exposure, for example, or unidentified factors that we seek to identify.

So what could be the cause of the variability in rates across states or why are some states higher or lower than others? Here are some factors that could contribute to those differences.

The first is state-based policies, including differences in health insurance coverage, such as Medicaid's policy coverage. This health insurance coverage has various interpretations and allowances within states that could translate to different rates of screening diagnosis and treatment across the different states.

We also know that there are several demographic indicators that are very highly associated with ADHD prevalence, and different demographic profiles across the states could reflect different rates from state to state. A specific example is poverty. We know that rates of ADHD are much higher in impoverished groups, and because of that, if we have states with higher rates of poverty then it is likely that we'll see higher rates of ADHD within those states.

There could also be state-based efforts around developmental screening and quality improvement that are very targeted and very aggressive, and again, that should lead to higher rates of ADHD diagnosis in that state, and North Carolina's certainly an example of that. They are definitely a state that has prioritized developmental screening and quality improvement and they have the highest rate of ADHD in the nation. It's not clear that that's directly accounting for that rate, but certainly it is probably a contributing factor.

There could also be differences in the practice patterns within states, including who typically treats a child with ADHD within the state, a specialist versus a primary care provider, for example, and also even continuing education characteristics that are tied to healthcare professionals tend to be associated with whether or not you have higher or lower rate of ADHD. And that's exemplified in a paper by Fulton and colleagues in 2009. There also could be different causal risk exposures across states and regions, and those factors could be investigated at the state level.

Now I'd like to turn the presentation over to my colleagues, Dr. Patsy Carter and Charlie Biss, who are representatives of state mental health programs in the child divisions.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

Thank you so much, Susanna. As a reminder, if you have a question for any of our speakers you can submit it online at any time using the form on the bottom right hand side of your screen that says, "Q&A."

Now I'd like to turn it over to Dr. Patsy Carter and Charlie Biss.

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

Thank you. My name is Charlie Biss, and Patsy and I are representatives of the National Association of State Mental Health Directors. We both represent the children and youth division.

The National Association for a long time has been—and mental health authorities across the state, have been very focused on individual disease model, and recently there's been an interest in looking more at the public health model and looking at promotion and prevention. And that really excites us, Patsy and I, and we became the co-chairs of the Public Health Subcommittee of the children's division. And we are here to really talk about how we're learning and using the work that Susanna has represented today in trying to really understand the public health model and understand a different way of looking at ADHD. I'll turn it over to Patsy.

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Yes, hi. Thanks, Charlie. As many of you know who work in state systems, the path to any goal is often very convoluted with lots of switchbacks and barriers, and my exposure to the public health model has kind of been that way. It started in the state of Missouri where our Department of Health and Senior Services, an agency that we had not partnered with extensively, came forward because of requests from school nurses who felt that they had a handle on working with kids with diabetes or asthma, but did not feel very comfortable working with kids who had problems, mental health problems, ADHD, depression, etc.

So we started planning a regional training for bringing together mental health providers and school health nurses and school administrators to kind of talk about this issue. It was so well received that we actually not only made a series of trainings around this to really start looking at what were some of the causal factors related to the mental health issues that school nurses were facing, but really to start creating collaboration.

We were lucky enough in the state of Missouri to get some foundation dollars to teach three communities about using the public health model. So during this process, I was having exposure to the public health model, which was very different, as Charlie had mentioned, kind of the disease focus model that mental health has often taken, even within say a system of care where we're looking more at the kids that have—kind of at the deep end of the system, with serious emotional disorders.

So we really began looking at this public health model to be able to switch how we viewed and served our populations, and this seems to have been very timely. We started our project about four years ago. Folks may know that in June of this year there was an article released in *Lancet* that noted that mental disorders are the leading cause of disability in young children. And this was what we were feeling in our states, across many states, that the number of children with mental health issues was growing and far exceeding our capacity and funding to be able to serve those children.

I know in the state of Missouri, public mental health funding is approximately only 20% of the kids can receive public funding services through the Department of Mental Health because of limitations in funding, and other states face that same issue.

So looking at the public health model became very timely for us, and with that, Charlie was another champion for the work that he had done in his state, and he'll share that with you. So we pulled together a public health workgroup through the children's division of the National Association of State Mental Health Program Directors to really begin this work. And we held a series of conference calls, talking and trying to educate folks on the public health model, promoting a shift away from the individualized disease model to a more population-based public health model in trying to create a learning collaborative.

Around that same time last year, the Center for Child and Human Development through the Georgetown University, with support from SANTA, released a public health approach to children's mental health, a monograph, really, about how we can apply the public health model to children's mental health. And Charlie, let me turn it over to you now to talk about your experiences in Vermont and what has led you to this point today.

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

We were starting an early childhood mental health system of care involving early childhood providers, and it became very clear that they were not interested in a disease focused individual model, but they were much more interested in a mental health social and emotional delivery model that would focus on all kids and work on more of a prevention model.

That really set a stage in our mental health authority so that when we were redoing our mission as a part of law, it became part of our law that we would implement a public health approach and look at the mental health of all Vermonters. And that was really a huge step in just looking at what our mental health authority would be doing for the next number of years. We're still working on how that will develop, but that certainly is a foundation to build on.

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Thanks, Charlie. So as we began, Charlie and I began sharing this workgroup and having our calls, we were noting that there really was kind of a struggle from the group around understanding the shift from an individualized disease model to the public health model, its use of data and how then, as Susanna had mentioned, kind of that iterative process of looking at certain risk factors.

So we kind of came to the conclusion that the use of data seemed to be one of the biggest challenges, because mental health authorities have lots of data, but it's predominately utilization data, and we have estimates regarding prevalence. Under the public health model, with taking a universal approach, it's not so much focusing on those that you are serving, but those who may have risk factors or certain disorders.



So we have been talking to the CDC in several of our dialogs because SANTA and CDC had started a small project of kind of sharing information, and that has really grown into the collaboration that we have now. And when the ADHD dataset came out last year, at that point we thought that this was what we had been looking for to be able to really wrap our hands around the data and be able to analyze that data in a totally different way than we had done before.

So with that we have been looking, and starting with our two states, to talk with CDC looking not only at the national data that Susanna presented, but also starting to look into our own datasets to be able to pull out the type of information that would help guide us. And looking at the growth of the diagnosis of ADHD in our states, and hopefully helping us to identify those risk factors or causal factors that we can impact this continued growth and reverse the trend.

So we're looking at how we can do collaboration, learning more about the datasets, looking at our analysis within each one of our states to see what may be the unique challenges we face in our state, and we hope to be able to start here with ADHD, start with Missouri and Vermont, but with that kind of knowledge on how the process works, be able to expand it not only to other states but also to other topics.

Charlie, anything you wanted to add on that?

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

No, I think I just want to really talk about the data that we first saw from Vermont from this study and some of our reactions to it and what we did as a result.

First of all, one of the areas that was not statistically relevant was the Medicaid population. And when I saw that I said, "Oh my God, we have 300% of poverty for Medicaid eligibility for kids. We're a very poor state. About a very high percentage of kids are on Medicaid. Something must be wrong." And then when I saw the non-insured, I was thinking that they probably are on Medicaid but didn't know it because we call it "Dr. Dynasaur" as a way of marketing, getting people health care. So that was one immediate piece that it just didn't feel like it looked correct and looked under represented.

A number of—when I looked at this data, I was really concerned about our increase in rate, especially since ADHD is often a gateway diagnosis into our system, because for the most part ADHD is identified in early childhood, in schools, and in primary care offices, and I knew that we had a very robust school mental health system. We have mental health workers in many of our schools, in early childhood, and we have a very robust pediatric community that does a lot of screening. So in some ways I wasn't surprised. I know that we really take screening as an important step so that was another reason that I thought that we might be high.

And then I looked at some of our Medicaid data within our state of just seeing what the percentages looked like in 2007, and what I found was that, just at the Medicaid population, 8.7% of the kids between 4 and 17 on Medicaid had a diagnosis of ADHD. And I was really interested to see if they were receiving medication, and 59.8% were actually receiving medication. And just learning to look at population-based data like this and working with CDC and asking the questions and trying to come up with the answers is just a very important and has been very helpful to me in trying to understand what the issues are in our state around this ADHD question. Patsy?

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Unlike Charlie, We don't have Dr. Dynasaur. We pretty much call it Medicaid here in Missouri, but to echo basically what Charlie said, what this has created for us is such an enthusiasm to dig deeper into the data that's available and finding new sources of data that we were not familiar with in the past.

Some of the hypothesis that I'm trying to examine in Missouri is we know that Missouri switched over to parts of the state having managed care in the 90s, and one of the outcomes of that is—one of the studies has shown that managed care increases access to services, particularly on the physical health side. And like Charlie had noted, ADHD is one of the those diagnoses that is often first diagnosed outside of the

mental health system, whether it's through the school or through a primary care physician. And so if by increasing access to healthcare, was this also leading to an increase in the rate? But because of our Medicaid data, initially was not –we were not able to make estimates from. We had to dig a little bit further in here.

Also from my experience, clinical experience, knowing the number of times that I had seen children that have a long history with ADHD, but it has been unresponsive to treatment, and then finding issues like trauma in their background and, as Susanna had mentioned, knowing that many of the symptoms of ADHD are also shared symptoms for other disorders. So wondering about the accuracy of the diagnosis and being able to find data sources to look back into trauma. And we do know that trauma is becoming more and more in the forefront of people's practice.

So it has offered us challenges and new ways to look at our data and new datasets to explore, which has been very exciting. So, Charlie, anything else you want to add?

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

I don't think so. I think we'll turn it over to Susanna.

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Great, thank you.

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Okay, great. So from my perspective, it's really exciting to hear from Patsy and Charlie this desire to implement a public health model within the context of something, a portion of the public health system that had really been very clinically oriented. And there is such a loss of state specific information and perspective within all of your states that I really cannot supplement sitting more at the Federal level. So unpacking these findings, it's just essential to have state representation and interested folks from within states to help us understand what the trends might be telling us and what are driving these trends. So this had been a really exciting collaboration.

Our overall anticipated steps in the plan collaboration, as we move forward, is to really assess each of the two states' data and information systems at a global level. And I plan to do that with a rapid assessment tool that won't take too much of Patsy and Charlie's time, but just to get a lay of the land in terms of what information and what data are available at the state level. And then to really develop in depth, descriptive, epi profiles for each state, similar to what you saw in the last two slides, but digging even deeper. What can the survey tell us that can help lead our discussions and lead the hypothesis generation for this issue?

We'll be analytically comparing the estimates, just as Charlie was mentioning. His Medicaid estimates were really actually very close to our, albeit, unstable Medicaid estimates within his state. But being able to compare them and putting them side-by-side gives us a check as to whether or not we're close from the survey perspective and the state perspective.

We'll also be able to evaluate the capacity of each state to explore factors within their state. What sorts of questions can they answer and where do they hit a dead end? Are there data deficits? Are there system connection deficits? And we'll be able to identify those through our discussions.

And then also to ultimately assist states in conducting statistical analyses, which we have the resources here to do to identify those state factors that may be associated with increasing prevalence with ADHD. And we can provide some of the resources to help support the state investigations.

As you can see, we have some empty seats in terms of collaboration. We'll certainly be moving forward with Charlie and Patsy, and giving them a lot of our attention because of their expressed interest and backgrounds and desire to move forward with this issue, but a major goal of all of ours is to really be able to translate the lessons learned from this collaboration to more states and also to other conditions. So if

you're interested in collaborating on this effort or something similar or you have questions for me about the analysis, certainly reach out to me. I have my e-mail address there. Or if you have questions for Patsy or Charlie, their information is here as well.

And I'd just like to thank all of you for attending this webinar, and I believe we have some time for questions.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

Yes, thank you both, Patsy and Charlie, and thank you again, Susanna, for your presentation earlier. It's been a very engaging program, and we already have some questions coming in.

As I mentioned at the beginning, we're going to be able to take questions both online and on the telephone. To post a question online, just enter your question in the field at the bottom of your screen, bottom right of your screen, that says "Questions," and hit enter.

So while folks on the phone are joining the queue, I'm going to start off with a few of the online questions that we've had come in.

The first question I have came from a couple of people. I think it's really for Susanna, and the question is, "Have there been any studies to ascertain why some states have higher rates than others? Have they looked at better diagnostic procedures or a more higher rate of doctors or physicians?"

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Great question. I think that that is ultimately a primary research question of our collaboration moving forward is to try to understand what's happening, what's explaining this variability across states. However, there has been some research to suggest that provider ratios definitely contribute, and that's really a reflection of access to care. If you have more access to care, you're more likely to get a diagnosis, not just of a behavioral disorder but of most health conditions generally.

There are also other factors definitely, the continuing education that I mentioned from the Fulton paper. If providers or health care professionals continue to hear about ADHD, they hear more about waiting room screeners that tend to have good reliability and they can do it in a rapid fashion, they're more likely to screen. So getting information out about useful tools, I think that's also true for the Bright Futures Initiative. All of those things tend to gear healthcare professionals and school professionals to turn to questioning about whether or not a child has ADHD, and that could account for some of the rates.

One other component is really that—you know, Vermont is actually—there was a Kids Count report that came out recently, I think it was actually a 2009 report that looked at the 2003 National Survey of Children's Health Data, and they were looking at how well states do for their children in poverty. And Vermont was ranked really high, and yet they had a significant increase in ADHD over time. So again, just because rates are higher in certain states or the increases are higher proportionally in certain states, doesn't necessarily indicate that something's wrong. It could mean that something's very right within that state. And I hope that answers the question.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

Okay, great. Well the next question I have from online is I think to anybody, and it is, "Do any states have population-based surveillance on ADHD?"

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

This is Susanna again. I can tell you that we do have, at CDC, two population-based longitudinal studies that were funded to look at ADHD screening within schools, and then inviting those children in for a diagnostic evaluation to do some population-based assessments. It's not surveillance because it wasn't

continued. The sampling was not continued over time, but those population-based studies were in South Carolina and Oklahoma. To my knowledge and in our discussions, Charlie and Patsy, I don't think that's come up in either of your states, and I don't know of that happening anywhere else either.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

I don't believe that we have any questions on the phone yet, but we have another question from online. It's from Ken Rosenberg who says that, "I've been talking with local educators to explore ways in which schools could work differently to increase chances of success for ADHD kids. The question is is anyone else talking with educators?"

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Charlie, you know you have a pretty cool program. Would you like to talk about that?

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

Our medical school has really developed an algorithm with the Department of Education and parents about how to work together around the diagnosis and treatment of ADHD so that neither one of the them is just dealing with this issue separately, and it also gives families a very good context to know that their primary care provider and their schools are working together. And that's been very successful.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

A kind of related question I have for Dr. Carter is, "Do you have a source where we could look to the education curriculum you used for school health personnel to teach about ADHD?"

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Actually this was a curriculum that we developed—Georgetown, the Center for Child and Human Development conducted. It was a very facilitated and interactive curriculum, and they do offer this for other states. So I would encourage you to contact Georgetown, particularly Ellen Kagen, who was our facilitator here.

We ended up doing a series of three regional trainings that were done over time that ended up being very successful. We would have anywhere from 100 to 300 participants in each of the regional trainings and we had five regions that we covered. So it seemed very successful in creating collaboration between community mental health centers, families, and schools. Being able to make facilitated referrals, and giving those school nurses the information that they need.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

I think that we have a question on the phone right now.

**M**

Are there any people who are working on trying to help educators change the way in which their schools function, the way they're structured to maximize the chance that ADHD kids can succeed? Things like systems where kids don't have to remember to write down assignments. Ways in which systems are developed so that when assignments need to be handed in it's less of a hassle for ADHD kids?

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

Yes. I think that one set of resources I would recommend is the National Resource Center, the program of CHADD. They do have a lot of resources, and really targeting schools and trying to work with school professionals to try to build good IEPs, to try to develop and advocate for your child who may have ADHD. There are a number of resources there.

Also, I think that there's some interesting work that Charlie referenced about placing some school mental health professionals within schools, and Charlie do you want to talk about that?

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

I will talk about that, and I'd also like to talk about a national educational movement that's called Positive Behavioral Support. And I know that in Vermont that has made huge differences, not just for kids with ADHD, but kids with all different kinds of disabilities or situations that keep them from learning at an optimal level. And it's really focused on creating a school atmosphere that keeps children in the learning environment as much as they can, and facilitates that kind of change.

And what's so different about that is that for so long we've been talking about making sure that kids are ready for schools, and this is a real movement to make sure schools are ready for kids and kids with all different situations that they come into school with. And to me, that is the area that we, as mental health people, and we have over 600 mental health workers in our schools in Vermont, and we're changing our practice as a result of working with positive behavioral supports, which really becomes much more of a school person that helps to coach and promote social and emotional wellness and that usually helps with the learning.

So I know that this is going on in a number of states, and it's certainly something that I would encourage, if it's not going on in your state, to talk to the education program about getting it involved. It really changes the environment of schools.

**Patsy Carter - Director, Children's Clinical Services Missouri Department of Mental Health**

This is Patsy. I would echo what Charlie said. We have a similar initiative here in Missouri, and I'm very supportive of the PBS or PBIS model because, just for what Charlie said, it really changes the environment. And to me this is very compatible with the public health model, because it takes both a universal approach to the entire school and then hopefully it helps support those kids who may need some additional support, but really changes that environment. And I think that's exactly the type of systems work that we need to be doing in states now. So I wholly support what Charlie offered.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

I think we've got time for a couple more questions. I have one question from Ricky, which is, "Were these questions included in the 2009-2010 survey, and were there any new questions related to ADHD?"

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Great question. The National Survey of Children's Special Health Care Needs actually runs off cycle with the National Survey of Children's Health, so that would be the one in the field 2009-2010. But in 2011 and 2012, that's the survey that's in the field, The National Survey of Children's Health, that's in the field right now, and there are a couple questions that have been added to all the condition questions. And, Dr. Kogan, I don't know if you want to chime in on that?

**Michael D. Kogan - Director, HRSA's Maternal and Child Health Bureau's Office of Epidemiology, Policy and Evaluation**

No, go ahead, Sue. You can continue.

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Generally, they're questions that follow up to, "Does the child have the disorder? Is the disorder current? The severity of the disorder," is now for all of those questions. And then for some of them age of diagnosis is added in. So I believe that the draft interview is posted on our website and also probably routed through MCHB. You can get that as well.

MCHB to their great credit and Dr. Kogan's credit, has really protected the condition questions when it's been very difficult. Everyone wants to add to the survey, but making sure that the condition questions and elements related to diagnosis are protected. That's really been a priority, and I think it's paying dividends now.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

I think we've got time for one more question from Cynthia, which is, "The use of a public health model for addressing ADHD is exciting. What are some of the emerging risk factors for ADHD on a population basis that could be used to develop the public health model?"

**Susanna Visser - Lead Epidemiologist, Child Development Studies Team, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Epicenters for Disease Control and Prevention**

Good question. I think we have a long, long list of potential factors have been suspected to increase either ADHD or ADHD-like behaviors. Everything from environmental exposures, brominated flame retardants, definitely lead exposure, there's been some concern that potentially exposure to high violence or just a significant amount of media exposure could cause symptoms that are consistent with ADHD, changes in parenting practices, inattentive parenting, that sort of thing.

All of these things are possible, and they really do range from environmental risk exposures all the way through to social risk exposures. And we are, as we move forward to try unpack these, the easiest ones to tackle are those that exist at a sociodemographic level. These characteristics of the family or characteristics of the state in terms of policy and practice that we can look for associations, and then continue to drill down to the extent that we have data within the states.

So I think that they have surveys that there are many options for what could be causing the increases, and we hope to tackle the hypotheses one at a time with the data that we have available first.

**Charlie Biss - Director, Child, Adolescent & Family Unit Vermont Department of Mental Health**

I think from a state perspective, we're excited to answer that question, and we'd love to come back when we know a little bit more about what's going on in our state. But that's the exciting process that I think we've begun.

**Sara Lifsey - DataSpeak Moderator, Maternal and Child Health Information Resource Center**

Well I think that's all the time we have for our discussion today. Answers to those questions that were not addressed during this Q&A period today will be posted in writing with the program archive. That archive will be available on the DataSpeak website in the next few weeks so you can access it at your convenience. If you think of any more questions, you can submit those to us via e-mail, the e-mail you see on your screen now, through the end of the week, using the e-mail address [mchirc@alcharum.org](mailto:mchirc@alcharum.org).

Before you go, we'd also like you to know that we will be broadcasting more DataSpeak programs in the coming months. Announcements about these future DataSpeak programs will be sent out via e-mail to everyone who registered for today's program, and announcements will also be posted on the DataSpeak website.

And finally, before you log out, we'd really appreciate it if you would take a moment to provide us with feedback on today's program. It's really important to us that we have your input on this session, as well as your recommendations for future programs. It's a very short survey, and to fill it out all you need to do is click on the evaluation link on the screen now. The survey will open up in a new window.

So today's program is now complete. Thank you to our speakers and to everyone in the audience for joining us. And we hope that you have a great afternoon.