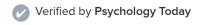
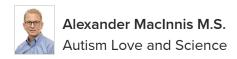
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### **AUTISM**

# Autism Controversies vs. the Evidence

We can resolve key autism controversies by using birth prevalence.

Posted September 11, 2023

Reviewed by Michelle Quirk









#### **KEY POINTS**

- There are several continuing controversies about autism tied to the true rate of increase of autism cases.
- Birth year cohort prevalence, a.k.a. birth prevalence, gives the rate of new autism cases.
- A new rigorous method produces accurate estimates of the birth prevalence trend and confounding effects.

There are many controversies about autism, and we're not close to resolving them. Many people hold strong beliefs on both sides of each controversy. Here are some key controversies:

- Autism is inherited from your parents with no environmental causes versus it must have environmental causes.
- The dramatic rise in the number of diagnoses results from things like increased awareness and broadened diagnostic criteria versus the number of people with autism has increased exponentially over the last few decades.
- There is a vast number of undiagnosed autistic adults versus there are relatively few autistic adults now, but there will be many more over the coming years.

Whichever version you may believe, the real question is *how* can we know what's true?

Before continuing, I need to address something. People use "autism" to mean different things. In this article, autism means the disorder professionally diagnosed according to official criteria.

## A real increase or artifact?

One basic fact underlies each of these controversies: The change over time in the number of autistic people born each year. In other words, how much of the increase is "real?" I was so intrigued by this question that I made it the topic of my master's thesis in epidemiology at Stanford several years ago, and I've continued to work on it since. But we don't need advanced methods to understand the basic answer because high-quality evidence is readily available, hiding in plain sight.

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fying a greater proportion of autistic individuals rather than there being more of them. Or, there are more autistic people simply because we've changed the criteria that define the disorder. The idea is that autism prevalence has been constant all along. But such claims typically don't cite evidence. Some papers include analyses or cite references, but as far as I can tell, none provide valid evidence to support the belief in constant prevalence. There is no known published explanation of why scientists believe in constant prevalence. I've asked other scientists and doctors but never received a good explanation.

# Problems with prevalence

Everyone talks about prevalence. But the way that word is normally used, it's not the right measure to look for an increase. Prevalence is the proportion of cases in a certain population at a specific time. It is not about the rate that cases occur.

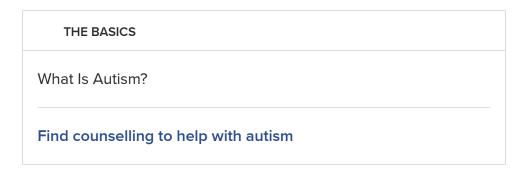
It's problematic to try to discern a trend by comparing prevalence over time. Prevalence studies at different years generally cover partially overlapping sets of birth years. That makes comparisons ambiguous. You can suggest various explanations for apparent increases, but there's no way to know which explanation is right. That makes it easy to believe whatever you want, including dismissing the simplest, most direct interpretation, which is simply a real increase.

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# Birth prevalence is the key

To understand the fundamentals of autism, we need to study the *time trend of the rate of new cases*. In epidemiology, incidence is the usual measure of the rate of new cases. But we can't use incidence for autism and other early childhood disorders. The best measure for the rate of new cases is the number of autistic people *born each year*. It's called **birth year cohort prevalence**, also called **birth prevalence**. This is textbook epidemiology.

The word "prevalence" in "birth prevalence" can be confusing. With the standalone term "prevalence," the population includes people of all ages—all birth years—unless you specify otherwise. In contrast, with birth prevalence, the population you're studying is those born in one specific birth year. By covering only one birth year per measurement, birth prevalence avoids the ambiguity that plagues plain prevalence. While you don't often see the term "birth prevalence" in articles about autism, it's what some important scientific articles mean by "prevalence."

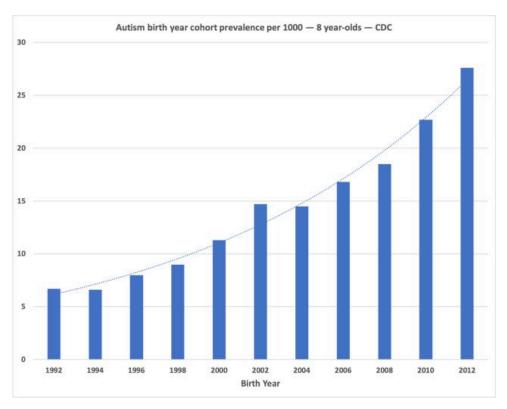


If the birth prevalence increased over a range of birth years, that would contradict several common beliefs. Something

lence is inheritance. You might think that "heritability" estimates from twin studies show that autism is inherited. But heritability doesn't mean what you probably think it means. I'll explore that in a future post.

I need to be clear about something to avoid misunderstanding. Increasing birth prevalence is *not* evidence that vaccines caused the increase. Many studies have examined that and found no evidence.

# Evidence hiding in plain sight



Autism birth prevalence from CDC reports

Source: Centers for Disease Control and Prevention

We already have high-quality evidence on birth prevalence. The Centers for Disease Control and Prevention's (CDC's)

remarkably valuable. But they don't say what most news reports claim.

#### **AUTISM ESSENTIAL READS**



Autism,
Adolescence,
and the
Creation of an
Identity



Autistic Meltdowns Help Me Live a Better

The CDC's ADDM studies do *not* give autism prevalence for children in general. They are not about people of all ages, either. Each prevalence report is about **children from one spe**cific birth year. That is, each report gives birth prevalence even though they don't call it that. It's right there in the title of each report. For example, "Prevalence... among children aged 8 years... 2020." There, the children turned eight in 2020, which means they were born in 2012. It's the birth prevalence for 2012. So far, the CDC has issued reports on birth prevalence of the even-numbered birth years 1992 through 2012. The CDC's website shows shows the assembled data for those birth years from their ADDM reports. These numbers show a 7.4 percent per year exponential increase in birth prevalence over those years. These CDC reports contradict the belief that prevalence and birth prevalence have been constant.

Published data from other sources, including the California Department of Developmental Services and the Danish National Patient Registry, also show large increases in birth prevalence over many years.

explanation.

# My research

My epidemiology thesis investigates how to determine how much of the increase in autism is real and how much is an artifact of other factors. It shows that the statistical methods available at the time were incapable of determining the truth.

Many papers have used unsuitable methods to try to determine the "real" increase in autism. Many attempt to show that the real increase is small or zero. A paper of mine in the journal *PLOS ONE* explores the fundamental flaws in the more credible methods used. Existing methods typically use circular reasoning. That is, researchers have to make assumptions to analyze the data, and the resulting analysis produces estimates that follow the assumption.

So, I created a new method called Time to Event Birth Prevalence Estimation (TTEPE). It's in the previously mentioned *PLOS ONE* article. TTEPE avoids ambiguity and the need for arbitrary assumptions. It produces accurate estimates of the birth prevalence trend, the trend in all diagnostic factors like awareness, and the effects of changes in diagnostic criteria, all at once.

Now, we have a suitable method. The data we need to analyze already exist. More papers are coming.

When you need real answers and solutions, follow the evidence.

Rotifinan KJ, Greeniana S, Lasti TL. *Modern Epidemiology*, Sta ed. Philadelphia: Wolters Kluwer, 2008, pp 47.

<u>CDC Autism and Developmental Disabilities Monitoring Network surveillance summaries. *MMWR*.</u>

CDC autism data

More









## **About the Author**



Alexander MacInnis, M.S., is an epidemiologist specializing in autism. He obtained his M.S. in epidemiology and clinical studies from Stanford, and is on the board of the Autism Society San Francisco Bay Area.

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# More from Alexander MacInnis M.S.

