

The American Statistical Association's Health Policy Statistics Section is raising serious concerns about a proposed NIH/CMS research project on Autism Spectrum Disorder (ASD) (<https://www.nih.gov/news-events/news-releases/nih-cms-partner-advance-understanding-autism-through-secure-access-select-medicare-medicaid-data>).

Specifically, the outlined research program by NIH/CMS has serious methodological flaws for prospective research, including:

- **The sample is unrepresentative:** The study only examines Medicaid-eligible families, excluding families with private insurance
- **The data source is inappropriate:** It uses Medicare/Medicaid data designed for aging studies, not autism research affecting primarily children
- **The data will have gaps:** Medicaid's "revolving door" creates data gaps as families change insurance status.
- **Aspects of the study violate basic ethical guidelines:** If the study includes individuals who are younger than 18 years, this would violate the rights of minors with ASD who cannot provide informed consent.

As a result, the study cannot determine autism trends across all populations, assess intervention effectiveness fairly, measure real economic burden on families, and investigate actual causes of ASD. That is, the study's design does not support the study's stated goals.

But there are good alternatives. Social Security disability services data are a strong data source, as are national/state educational databases. Studies can be designed that include both Medicaid AND privately insured populations and do not require a registry.

We ask Congress and the Administration to fix these flaws. Our children with autism deserve rigorous, ethical research that can effectively inform policy and improve care—not flawed studies that risk wasting resources and perpetuating inequities.

Contact your representatives today. Science integrity matters. Our families matter.

#AutismResearch #Congress #NIH #HealthPolicy #DataScience #Statistics #PublicHealth
#AutismAdvocacy